

Illinois Statewide Transition Plan to Comply with the Department of Health and Human Services Centers for Medicare and Medicaid (CMS) 2249-F and 2296-F Regarding Home and Community-Based Services (HCBS) Settings Rules in Illinois' 1915c Waivers

Overview of Transition Plan

Federal rules published on January 16, 2014 and March 17, 2014 require that all federally-approved 1915c waivers comply with regulations for Home and Community-Based Services (HCBS) settings as described in 42 CFR 441.301(c) (4) (5) and 441.710(a) (1) (2). Each State operating a 1915 c waiver is required to develop a Statewide Transition Plan which will describe to the Centers for Medicare and Medicaid (CMS) Illinois' assessment of its current waiver programs and discuss proposed remediation strategies necessary to ensure full compliance with the new rules. This Plan may be found at:

<http://www2.illinois.gov/hfs/MedicalPrograms/HCBS/Transition/Pages/default.aspx>;

Components of the Illinois Statewide Transition Plan

Illinois' Statewide Transition Plan includes an assessment of existing State statutes, regulations, standards, policies, licensing requirements, and other provider requirements, including whether waiver settings' comply with the regulations as outlined at 42 CFR 441.301(c)(4)(5) and 42 CFR 441.710(a)(1)(2). Furthermore, the Statewide Transition Plan describes the remediation steps Illinois plans to implement to assure full and on-going compliance with the HCBS settings requirements, with specific timeframes for already-identified actions and deliverables. The Statewide Transition Plan will be modified as additional actions and timeframes are identified.

The development of the Illinois Statewide Transition Plan is subject to public input, as required at 42 CFR 441.301(6)(B)(iii) and 42 CFR 441.710(3)(iii) and describes the process Illinois utilized for obtaining initial stakeholder input as well as plans to maintain stakeholder dialogue as the Transition Plan is modified.

Background

On January 16, 2014, the Department of Health and Human Services, Centers for Medicare and Medicaid (CMS) published final rules (2249-F and 2296-F) impacting the 1915c, 1915i and 1915k Medicaid authorities. The rules require States to ensure that individuals receiving Long-Term Services and Supports (LTSS) have full access to the benefits of community living and the opportunity to receive services in the most-integrated setting appropriate and those rights and privileges are comparable to those afforded to Non-Waiver participants in the community.

Prior to the final rules, Home and Community Based (HCB) setting requirements were based on location, geography, or physical characteristics. The final rules define HCB settings as more process and outcome-oriented and guided by the waiver participant's person-centered plan.

This occurs by:

- Being integrated in and supporting full access to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, with the same degree of access as individuals not receiving HCBS waiver services;

- Giving individuals the right to select from among various setting options, including non-disability specific settings and an option for a private unit in a residential setting;
- Ensuring individuals rights of privacy, dignity and respect, and freedom from coercion and restraint;
- Optimizing autonomy and independence in making life choices, including daily activities, physical environment and with whom to interact; and
- Facilitating choice regarding services and supports, and who provides them.

These final regulations were the result of several years of public and stakeholder comment beginning as early as 2011.

In the spring of 2014, Illinois convened an LTSS Inter-Agency workgroup consisting of representatives of: the Illinois Department of Healthcare and Family Services (HFS) as the State Medicaid Authority responsible to federal CMS for all of the State's nine 1915c waivers; the Illinois Department of Human Services (DHS) and its Divisions of Developmental Disabilities (DDD), Mental Health (DMH), Alcoholism and Substance Abuse (DASA), Rehabilitation Services (DRS); the University of Illinois at Chicago Division of Specialized Care for Children (DSCC); and the Illinois Department on Aging (IDoA). These State agencies, with the exception of the DMH and DASA, are the operating agencies for one or more of the State's nine HCBS waivers, which include:

1. HCBS Waiver for Adults with Developmental Disabilities
2. Residential Services for Children and Young Adults with Developmental Disabilities
3. Support Waiver for Children and Young Adults with Developmental Disabilities
4. HCBS Waiver for Children Who Are Medically-Fragile, Technology-Dependent
5. HCBS Waiver for Persons who are Elderly
6. HCBS Waiver for Persons with HIV or AIDS
7. HCBS Waiver for Persons with Brain Injury
8. Persons with Disabilities
9. Illinois Supportive Living Program

Assessment of Current Level of Compliance

Legal Review of State Statutes, Policies and Procedures

Under the leadership of the HFS General Counsel's Office, each State agency's legal and program staffs along with representatives of the Governor's Office of Statewide Housing Coordination conducted a review of Illinois' regulations, State statutes and waiver policies and procedures across the nine HCBS waiver programs to assess compliance with the residential and non-residential settings regulations. A matrix that identifies State Statutes, Policies and Procedures is included in the Transition Plan, Appendix A. As the action steps identified in Appendix A are implemented, the State may determine that no action is required as well as further actions are needed.

Assessment of Provider Compliance with Residential and Non-Residential Settings Requirements

The LTSS Inter-Agency workgroup has met regularly since April, 2014 and will continue to meet throughout the implementation of the Statewide Transition Plan. Initially, the workgroup's focus was on understanding the new regulations and the specific requirements for the development of the Statewide Transition Plan. Subsequently, its focus was on assessing the State's current compliance. The assessment phase included the collaboration with an independent, outside entity, the University of Illinois at Springfield (UIS) to design provider residential and non-residential setting surveys; convene a smaller workgroup that included

representation from State agency's legal teams to review existing State statutes, administrative rules, and provider requirements to determine language that would need to be amended to comply with the new regulations; and participation in numerous stakeholder engagement events to dialogue with external stakeholders concerning the new HCBS regulations and their potential impact on the LTSS system. In the fall of 2014, stakeholder engagement events included presentations to Illinois Association of Rehabilitation Facilities (IARF), Affordable Assisted Living Coalition, Illinois Governor's Conference for Aging and Disability, and a number of workgroups associated with efforts of the Illinois Governor's Office of Health Information and Transformation and the Balance Incentive Program (BIP).

Surveys

The Department of Healthcare and Family Services worked with the University of Illinois – Springfield's Survey Research Office to assist the LTSS Inter-Agency workgroup with the development of the methodology for the residential and non-residential settings surveys including the development of survey questions and analysis of survey responses to provide the State with a non-biased assessment of current practices. The survey questions were reviewed by each State agency, tested with staff from several community-based HCBS waiver residential settings and revised by the workgroup so as to be inclusive of the variety of services offered in Illinois' residential and non-residential HCBS settings. Two versions of the survey were created: one for residential settings and one for non-residential settings providing HCBS waiver services.

Residential Settings

The residential survey, itself, consisted of two surveys: an agency-specific survey and a setting-specific survey. Researchers from the Survey Research Office, assisted in the survey design, completion and analysis of the results. A copy of their report is attached to this Draft Statewide Transition Plan as Appendix B. As with this Draft Statewide Transition Plan, Appendix B is also a DRAFT, as outstanding data may slightly alter the findings in a final report.

The names of 256 community-based agencies operating residential HCBS waiver settings were provided to UIS by the State agencies. Between September and November 2014, the surveys were sent to all of these HCBS providers. Multiple copies of the setting-specific survey were sent to each agency so that agency staff could report on each residential setting operated by its agency. In an effort to maximize the number of responses, UIS researchers sent post card reminders and a second set of surveys. Surveys could be submitted electronically or through the US mail. Providers who had not responded by a certain date were called and their surveys were completed over the phone. 244 of the 256 agencies (95%) completed surveys. These agencies operate 1659 residential HCBS settings in Illinois. Agencies which do not complete surveys will be contacted to confirm that they plan to continue to participate in providing HCBS waiver services to program participants. Provider sites that do comply with completion of the surveys will be visited for validation and monitoring purposes.

Non-Residential Settings

The non-residential survey, itself, consisted of two surveys: an agency-specific survey and a setting-specific survey. Researchers from the Survey Research Office, assisted in the survey design, completion and analysis of the results. A copy of their report is attached to this Draft Statewide Transition Plan as Appendix C. Appendix C is also a DRAFT, as outstanding data may slightly alter the findings in a final report.

The names of 218 community-based agencies operating non-residential HCBS waiver settings were provided to UIS by the State agencies. Between October and December 2014, the surveys were sent to all of these

HCBS providers. Multiple copies of the setting-specific survey were sent to each agency so that agency staff could report on each non-residential setting operated by its agency. In an effort to maximize the number of responses, UIS researchers sent post card reminders and a second set of surveys. Surveys could be submitted electronically or through the US mail. Providers who had not responded by a certain date were called and their surveys were completed over the phone. 205 of the 218 (95%) completed surveys. These agencies operate 409 non-residential HCBS settings in Illinois. Agencies which do not complete surveys will be contacted to confirm that they plan to continue to participate in providing HCBS waiver services to program participants. Provider sites that do comply with completion of the surveys will be visited for validation and monitoring purposes.

Documents Related to Surveys

Copies of the letters of introduction, blank survey forms, the Executive Summaries and the analysis of the responses to the surveys can be found at the Illinois Department of Healthcare & Family Services website at: <http://www2.illinois.gov/hfs/MedicalPrograms/HCBS/Transition/Pages/default.aspx>;

Program Infrastructure Compliance and Estimates of Sites in Compliance

The State's methodology for assessing compliance for both residential and non-residential HCBS settings includes a stratification of the groupings based on an evaluation of the level of their current compliance with the federal regulations.

Description of Setting

The survey results will assist the State in determining settings that will be targeted for a follow-up survey result validation site visit. The survey results will inform the State as to system wide changes that need to occur, including amendments to statutes, administrative rules and regulations, as well as specific changes related to potential sites that might fall under the heightened scrutiny category. Sites may fall into one of three groupings as defined by the methodology and subsequent categorization of the data and recommendations of UIS in each of the survey reports (See Appendices B and C): Both residential and non-residential surveys had questions relating to the location of the site.

The following question was asked:

Which of the following best describes your setting:

- ☐ *Physically connected to a hospital, nursing setting, institution for mental disease, or an intermediate care setting for individuals with intellectual disabilities.*
- ☐ *Not physically connected but on the grounds or adjacent to a hospital, nursing setting, institution for mental disease, or an intermediate care setting for individuals with intellectual disabilities.*
- ☐ *Not physically connected or adjacent hospital, nursing setting, institution for mental disease, or an intermediate care setting for individuals with intellectual disabilities.*

The categories were identified in the federal CMS guidance dated September 5, 2014 titled, *Statewide Transition Plan Toolkit for Alignment with the Home and Community-Based Services (HCBS) Final Regulation's Settings Requirements*.

The four federally defined categories are:

1. Fully align with the federal requirements.

Illinois estimates that 1585 residential sites and 375 non-residential sites meet the federal requirement. It should be noted that these sites appear to align with federal requirements. Many of these sites may require modification to policies and practices in order to comply fully.

2. Do not comply with the federal requirements and will require modification.

Illinois estimates that 58 residential sites and 28 non-residential sites do not comply with the federal requirement and will require modification. An action plan will be developed for sites requiring modification.

3. Cannot meet the federal requirements and require removal from the program and/or relocation of participants.
4. Presumably non-home and community-based, but for which the State will provide justification/evidence to show that those settings do not have the characteristics of an institution and do have the qualities of home and community-based settings (heightened scrutiny).

For categories #3 and #4, the State is combining its estimates. While 16 residential and 6 non-residential sites appear based upon their response to this survey question do not meet the federal requirement, it is only after site visits to validate the survey results and conversations with the management and staff of the site regarding federal rules, that the State can make the final determination to remove the site as an option for waiver participants or recommend for heightened scrutiny.

The processes for determination of heightened scrutiny are defined elsewhere in this Transition Plan document.

There was a requirement to complete the survey by individual setting sites. However, the actual surveys were completed by provider agencies – self reported. Consequently, Illinois can only provide estimates. All sites that fall into categories 2, 3 and 4 above will have site visits, with a sample selection of sites that fall in category 1. Since the State will be visiting only a sample of sites in category 1, these sites will be monitored for compliance through on-going site visits that are conducted as part of our waiver quality assurances.

Level of Autonomy and Frequency of Behavior

Most of the survey questions fell into categories pertaining to Levels of Autonomy and Frequency of Independent Behavior. In response to these sets of questions, all the sites are presumed to fall into categories 1 or a combined category representing, 2, 3 or 4. No site will require removal or heightened scrutiny based upon policies and procedures. The State's plans to modify its statutes and language relating to rules, policies and procedures will bring those sites that need strengthening into compliance during the next four years.

Analysis of the data pertaining to Levels of Autonomy and Frequency of Independent Behavior were categorized into three groupings. These groupings are:

1. Completely meet expectations or full compliance -- These are community-based HCBS waiver settings that scored between 2 and 5 on the “Level of Autonomy” and between 2 and 4 on the “Frequency of Independent Behavior” scores on the survey instruments;
2. Partially meet expectations or appearing not to meet expectations, but may present evidence showing that they do have the qualities of HCBS settings -- These are entities that scored below a 2 on the “Level of Autonomy” and “Frequency of Independent Behavior” scores on the survey instruments.
3. Do not meet expectations -- These are entities that are reporting to be physically connected to a hospital, nursing facility, institute for mental diseases, or a public intermediate care facility for individuals with intellectual disabilities.

The State plans to conduct site visits to validate the results of the surveys to a representative sample of sites falling into categories 1 and 2. These would be the same sites that fall into federally defined categories of: 1) fully align or 2) do not comply with the federal requirements and will require modification.

The State plans to conduct site visits to all sites in category 3. These are sites that fall into the federally defined categories of: 3) cannot meet the federal requirement and require removed from the program and/or the relocation of individuals or 4) are presumptively non-home and community-based but for which the State will provide justification/evidence to show that those settings do not have the characteristics of an institution and do have the qualities of home and community-based settings. During these site visits, the entity maybe asked for additional documentation which addresses those areas identified in its setting specific survey which appear not to be in compliance with the new regulations.

Site visit objectives

First, while the survey was required, it was a self-administered instrument and the intent as described in correspondence from the State was to obtain a “snapshot” of existing compliance. Consequently, the survey responses need to be validated through site visits. Those community agencies that self-identified the location of their settings as being connected to or on the grounds of an institutional setting will need immediate attention and an individualized plan developed to comply with the new regulations. The plan will address the State’s collaborative efforts to assist the community agency to come into compliance with the new regulations.

Additionally, the State plans to obtain consumer and family feedback as a component of the site visits, including the formation of focus groups and individualized surveys with key stakeholders in addition to meetings with consumer participants and their circle of support during site visits. These qualitative methods will inform recommendations should the site fall under the “Heightened Scrutiny” category as described in the regulations.

Secondly, the validation of the survey results through the site visits will further inform the State as to the system wide changes that will need to be made to statutes, policies and procedures. The State anticipates that some HCBS waiver provider agencies are likely to be models of best practice and other community agencies may be candidates to learn from these best practices.

The State’s methodology for assessment of compliance with the new regulations, including the qualitative methods described above, will inform and produce specific recommendations regarding system wide

changes that will promote individual autonomy and community integration. The resulting recommendations will be used to define the process and the content of changes to State statutes, State agency departments' policies and procedures and the requirements of particular sites' policies, procedures and practices.

It is expected that at the conclusion of all site visits, an update to the matrixes (Appendices A & G) will occur as well as the development of individualized action plans for sites that require change.

Independent approach to site visits

Residential and non-residential provider surveys were self-administered surveys that provided the State with an initial assessment of compliance with the new regulations. The State values an independent approach to the validation of the survey results that incorporates skilled reviewers that are open to discovery. The State intends to develop a multi-disciplinary team to conduct the site visits.

Development of validation survey instrument for site visits

Federal CMS provided additional guidance to States in late 2014 in a document titled: *Exploratory Questions to Assist States in Assessment of Non-Residential Home and Community-Based Service (HCBS) Settings* and found at: <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/exploratory-questions-non-residential.pdf>. These exploratory questions will be used in determining compliance with the non-residential settings' regulations. Illinois plans in early 2015 to develop a validation survey instrument that uses the exploratory questions as a basis to assess or measure the survey results and assists with the development of the State's remediation plan.

A sampling of participants and stakeholders will be interviewed in small on-site focus groups as part of the site survey and administration of the survey instrument described above. The results of these interviews will also be used to help the State determine remediation strategies and as described above, inform our recommendations that define the process and the content of changes to State statutes, State agency departments' policies and procedures and the requirements of particular sites' policies, procedures and practices.

Information gained through these interviews is critical in the identification of sites requiring "Heightened Scrutiny". It is through all of these investigative actions as to the status of the HCBS setting that planned remediation will occur as needed.

Communication/Stakeholder Input

Website

The Illinois Department of Healthcare & Family Services (HFS) established a website to inform Stakeholders on the new HCBS waiver regulations as well as maintain interactive communication regarding the Draft Transition Plan. The URL for that website follows:

<http://www2.illinois.gov/hfs/MedicalPrograms/HCBS/Pages/default.aspx>

The webpage includes general information about the new HCBS regulations, including links to the final regulations as included in the Federal Register (42 CFR 441.301 c (4)(5) and 441.710(a)(1)(2) as well as CMS specific guidance and Fact Sheets on the HCBS settings requirements. There is a link to an e-mail address where feedback and questions from the public may be submitted. Summaries of comments made electronically or mailed to the State, as well as answers to comments and questions posed to the State at

public forums, will be posted on this website. Information regarding opportunities to participate in Public Forums in order to learn more about the new regulations and/or to present comments to the State is listed on this webpage. Information regarding requesting hard copies of the Transition Plan is also available on this website. A telephone number and mailing address are provided. Once the Transition Plan is revised to incorporate stakeholder feedback received from various sources – participants, their families, service providers, advocacy groups, and the public at large – a revised Transition Plan will be posted to the website.

Public Notice and Flyer

A public notice and/or flyer will be distributed by the State to the providers and advocacy groups who, in turn, will be requested to distribute it to their participants/members. In addition, this public notice is to be sent to the Indian Health Service, Illinois' designated representative of First Nation constituents in our State. This notice will provide a brief description of the new rule and its requirements. It will provide the link to the website as well as a mailing address and a phone number which the public can use to request a paper copy of the Transition Plan and to make comments or ask questions. It will also list the details regarding six Public Forums which will be held. The Public Notices may be found in Appendix D and E. The flyer may be found in Appendix F.

Webinar

The State has scheduled a webinar in February, 2015. This webinar is targeted to – HCBS waivers providers and provider organizations and to HCBS waiver participants and their families, guardians and representatives. Information regarding this webinar may be found in Appendix F. It will include a “Chat” feature. A log of the Chat Box will be maintained with all comments documented and used to inform the development of the Statewide Transition Plan. The webinar will provide a phone number and a mailing address to which the public can direct their comments and questions.

Regional Public Listening Forums

Six Regional Public Listening Forums will be held at accessible locations throughout the State during the 30-day public comment period originally planned for January 15, 2015 - February 15, 2015 and subsequently extended to February 24, 2015. There is no cost to attend. Parking is available at all locations. Attendees will be informed of the new HCBS regulations and its implications for HCBS settings and will be given the opportunity to provide feedback and to ask questions. Those who comment will be asked to submit a written version of their comments at the Forum. These comments and questions (with responses) will be posted to the website. Attached to this document in Appendix D and E, are the public notices that were used to inform stakeholders of these forums.

The following is the list of the planned public forums:

PUBLIC FORUM SCHEDULE		
Thursday January 29, 2015	Parkland College Room W-115 2400 West Bradley Ave Champaign, IL 61821	10:30am – Noon
Thursday January 29, 2015	EPIC 1913 West Townline Rd Peoria, IL 61612	3:00pm – 4:30pm

Tuesday February 3, 2015	Spring Ridge Senior Housing Community Room 6645 Fincham Dr Rockford, IL 61108	1:30pm – 3:00pm
Wednesday February 4, 2015	University of Illinois-Chicago Disability, Health & Social Policy Building Auditorium, Room 166 1640 West Roosevelt Rd Chicago, IL 60608	10:30am – Noon
Wednesday February 4, 2015	The ARC 20901 LaGrange Rd, Suite 209 Frankfort, IL 60423	2:00pm – 3:30pm
Tuesday February 10, 2015	Rend Lake College Student Center – Private Dining Area 468 North Ken Gray Parkway Ina, IL 62846	1:00pm – 2:30pm

Communication with the Regional CMS Project Officer

The Draft Statewide Transition Plan will be forwarded to the Regional CMS Project Officer.

Communication with Provider Organizations and Consumer Groups

Over the past six months, representatives from the Illinois Department of Healthcare & Family Services (HFS) as well as sister agencies, have provided presentations on the new HCBS regulations at numerous conferences and workshops, including the Annual Governor’s Conference on Aging & Disability Conference, the Illinois Association of Rehabilitation Facilities Annual Conference, the Illinois Council on Developmental Disabilities monthly meeting, the Supportive Living Facility Association monthly meeting, the Medicaid Managed Care Association monthly meeting, and the Governor’s Office of Healthcare, Innovation and Transformation monthly meetings.

Remediation Strategies

Revision of Administrative Codes, Statutes and Waivers

As part of this Transition Plan, an initial legal and policy review of Illinois’ existing administrative rules, statutes, regulations, and licensing standards was completed by counsel and policy staff of each impacted State agency and/or divisions that operate HCBS waivers. This review included the identification of codes and statutes that may need to be amended in order to comply with the new HCBS regulations. During the first year of implementation, further review with specific remediation strategies, including changes in licensing and provider qualifications and language will be developed. Responsible parties within each State agency will be required to ensure that actions to implement these changes are taken, overseen by HFS General Counsel’s Office. A plan to affirm compliance regarding administrative codes, statutes and waivers may be found at in Appendix A.

Agency and Program Procedures and Policies – System wide Compliance Strategies

The State’s remediation strategy intends to encompass both system wide compliance and provider-specific compliance. Based on further analysis of the survey responses, information gained during site visits, and comments from the public, advocacy groups, participants and families, the State anticipates making revisions

to policies and procedures in the areas of autonomy, community engagement, transportation, employment opportunities, and settings' amenities and accommodations. An analysis of HCBS waiver service definitions will be completed in the first year. A review of program descriptions, factsheets and electronic and hard copy versions of informational materials will be completed to ensure compliance with the new regulations.

Based upon follow-up site visits to provider settings, the State agencies under whose jurisdiction these settings operate along with the Department of Healthcare & Family Services, will notify providers who are not in compliance with the new regulations. Specific explanations are to be presented to the providers regarding areas of their service setting and practice which do not comply with the new regulations. Timeframes for coming into compliance are to be outlined by the State agencies and appear in Appendix F. While the development of specific strategies to bring providers who are not in compliance are incorporated into the Transition Plan, the process for coming into compliance may include the following steps:

- Providers may implement requested changes and/or provide additional information;
- The State may provide guidance regarding areas needing additional remediation and establish timeframes for remedial actions to be completed;
- Provider groups under the direction of the State may work together to assist each other in bringing their programs into compliance;
- Providers may submit scheduled progress reports to the State on the changes they are making;
- Successful actions completed by providers to bring their settings into compliance may be posted on the HFS website, in order to inform the public as well as assist other providers;
- The State may complete an on-site visit to assure that required changes have been made.

The "Heightened Scrutiny" Process

The State intends to make a recommendation as to whether Illinois' HCBS settings qualify for "Heightened Scrutiny" on a case-by-case basis. The State will complete an on-site visit and obtain public/stakeholder input in order to make a determination regarding the setting's "Heightened Scrutiny" classification. The State may request additional stakeholder feedback and documentation from the setting provider in order to make an informed decision regarding the status of the site in relationship to the regulations. Once the State reaches a decision regarding the status, it will forward this recommendation and the accompanying documentation to CMS. CMS will subsequently report its decision to the State. Depending upon the decision reached by CMS, the State, in collaboration with the setting provider, will determine if any remediation steps are necessary.

Relocating HCBS Waiver Participants

The State intends to work with HCBS waiver providers to bring their settings into compliance with the new regulations. When remediation actions have failed, it will become necessary to inform participants and their families, guardians or representatives that an alternate compliant setting will need to be selected. Recognizing the significant consequences of this disruption for the participants, this action of terminating service provision at a non-complying setting will be taken only when all alternatives have been exhausted. Efforts will be made to notify the participants of the need to select an alternate location and of the various service settings available as soon in the process as possible. With any transition, the participant will be offered informed choice of available options. The best efforts by all entities involved including the State and care coordinators will be maximized to ensure the participant's health, welfare and safety and a smooth and seamless transition.

Revising Provider Requirements

In addition to the analysis of *State* statutes, policies and procedures, the State intends to review the existing HCBS waiver service definitions and provider contract language, and revise if necessary, to ensure compliance with the new federal HCBS regulations. Similar language will also be included in the State's managed care contracts to ensure compliance with federal CMS HCBS settings requirements.

Implementation of Consistent, Statewide Provider Training

The State will develop and deliver a consistent training curriculum that incorporates the vision of the new HCBS regulations as well as the compliance requirements. Initial training topics to be addressed include: facilitation of informed choice, community inclusion, philosophy of person-centered planning and the development of a person-centered plan, participant directed services and supports, and the dignity of risk. The State intends to make waiver participants and their families/guardians aware of the new rules and their impact on the services in which they participate.

Ongoing Compliance

As part of the annual review of the participant's person-centered plan, feedback will be sought from the participant and the participant's family or guardian regarding the access to community activities, choice of accommodations, roommates, and services. In addition, the annual review should validate the inclusion of participant goals and satisfaction with services. A template will be created or existing forms modified to ensure that these topic areas are covered during that review. Family members or guardians will be included in this process, as appropriate. Waiver participants and/or family members and guardians will continue to be informed of the mechanism for providing concerns or complaints. A statement of the participant's rights will be created or existing forms modified and distributed to the participant and guardian as appropriate.

Regularly-scheduled on-site audits completed by the State, or entities contracted with the State that oversee HCBS performance measures, will incorporate reviews of all revised materials, including the person-centered plans that note the options offered and the choices made by the participant or his/her guardian. In collaboration with each of the operating waiver agencies, HFS will review the current waiver assurances and revise as necessary to comport with the new regulations. Subsequently, accompanying performance measures may be added that gauge choice and community integration. These will be included during the quality assurance reviews conducted by the External Quality Review Organizations (EQRO) as well as those conducted by the State departments and divisions.

Settings found to be out of compliance with the new regulations during these routine reviews will be required to submit and have approved a corrective action plan which includes a timeframe for its completion. Failure to complete that plan may jeopardize the agency's certification and participation in the waiver program.

The HFS website with its link to an e-mail address will continue to be an option for those who want to provide feedback, ask questions or express their concerns to HFS regarding any of the settings offering home and community-based waiver services.

The State will monitor progress on the implementation of the Statewide Transition Plan on an ongoing basis and will regularly report on the status of the implementation, through posted updates on the HFS website. There will continue to be an opportunity for public comment and input provided through the website.

Action Steps and Timetable to Bring Illinois into Compliance

The work plan illustrating Illinois' identified action steps and timeline for all deliverables to bring the State into compliance with the federal rules may be found in Appendix G of this Plan. This document, along with the whole Plan is viewed as a process. As the state continues its assessment and remediation strategies, it may discover additional policies, procedures and forms that will require modification.

Appendix A State Statutes, Policies and Procedures			
Cite State Regulation and/or Licensing Requirements (Insert Rule & Chapter #'s)	Summary of State Regulation - Include Existing Language	Action Steps	Targeted Completion Date
APPLIES TO ALL ILLINOIS WAIVER PROGRAMS - HCBS Waiver for Persons with Brain Injury 0329, HCBS Waiver for Persons with HIV or AIDS - 0202 and Physically Disabled - 0142, HCBS Waiver for Persons Who are Elderly - 0143, Illinois Supportive Living Program - 0326, HCBS Waiver for Adults with Developmental Disabilities - 0350, Support Waiver for Children and Young Adults with Developmental Disabilities - 0464; Residential Waiver for Children and Young Adults with Developmental Disabilities - 0473, HCBS Waiver for Children who are Medically Fragile, Technology Dependent - 0278			
89 IL Admin Code Chapter I - Department of Healthcare and Family Services	140 Subpart A - General Provisions	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter I - Department of Healthcare and Family Services	140 Subpart B - Medical Provider Participation	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

89 IL Admin Code Chapter I - Department of Healthcare and Family Services	140 Subpart C - Provider Assessments	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter I - Department of Healthcare and Family Services	140 Subpart D - Payment for Non-Institutional Services	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter I - Department of Healthcare and Family Services	140 Subpart E - Group Care	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

WAIVER PROGRAMS OPERATED BY DHS-DRS - HCBS Waiver for Persons with Brain Injury 0329, HCBS Waiver for Persons with HIV or AIDS - 0202 and Physically Disabled - 0142,			
89 IL Admin Code Chapter IV - Department of Human Services	676.10 through 676.40 - General Program Provisions	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter IV - Department of Human Services	676.100 through 676.150 - Case Management	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter IV - Department of Human Services	677.10 through 677.200 Customer Rights and Responsibilities	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

89 IL Admin Code Chapter IV - Department of Human Services	679.10 through 679.50 - Determination of Need (DON) and Resulting Service Cost Maximums (SCMS)	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter IV - Department of Human Services	681.10 through 681.70 - Prescreening	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter IV - Department of Human Services	682.10 through 682.520 - Eligibility	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

89 IL Admin Code Chapter IV - Department of Human Services	684.10 through 684.100 - Service Planning and Provisions	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter IV - Department of Human Services	686.10 through 686.800 - Personal Assistants	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter IV - Department of Human Services	686.100 through 686.140 - Adult Day Care Providers	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

89 IL Admin Code Chapter IV - Department of Human Services	686.200 through 686.280 - Homemaker Services	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter IV - Department of Human Services	686.300 through 686.350 - Electronic Home Response Services	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter IV - Department of Human Services	686.400 - Maintenance Home Health Provider Requirements	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

89 IL Admin Code Chapter IV - Department of Human Services	686.500 - Home Delivered Meals	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter IV - Department of Human Services	686.600 through 686.640 - Environmental Modifications	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter IV - Department of Human Services	686.700 through 686.730 - Assistive Equipment	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

89 IL Admin Code Chapter IV - Department of Human Services	688.10 through 688.70 - Illinois Long-Term Care Partnership Program	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
Applies Only to HCBS Waiver for Persons with Brain Injury 0329			
89 IL Admin Code Chapter IV - Department of Human Services	686.1000 through 686.1040 - Case Management Services to Persons with Brain Injuries	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter IV - Department of Human Services	686.1100 through 686.1140 - Behavioral Services Provider Requirements	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

89 IL Admin Code Chapter IV - Department of Human Services	686.1200 - Day Habilitation Services for Persons with Brain Injury	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter IV - Department of Human Services	686.1200 - Day Habilitation Services Provider Requirements	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter IV - Department of Human Services	686.1300 - Prevocational Service - Provider Requirements	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

89 IL Admin Code Chapter IV - Department of Human Services	686.1400 - Supported Employment Service Provider Requirements	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
Applies Only to HCBS Waiver for Persons with HIV or AIDS			
89 IL Admin Code Chapter IV - Department of Human Services	686.900 through 686.940 Case Management Services to Persons with HIV or AIDS	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
HCBS Waiver for Persons Who are Elderly - 0143			
89 IL Admin Code Chapter II -Dept on Aging	240.160 - Definitions	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

89 IL Admin Code Chapter II -Dept on Aging	240.210 - In-Home Service	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter II -Dept on Aging	240.230 - Adult Day Service	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter II -Dept on Aging	240.235 - Emergency Home Response Service (EHRS)	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

89 IL Admin Code Chapter II -Dept on Aging	240.237 - Automated Medication Dispenser	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter II -Dept on Aging	240.1505 through 240.1590 - Providers	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
IL Dept on Aging Program Instruction Manual (PIM)		The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

IL Dept on Aging RFQ for Adult Day Service		The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
HCBS Waiver for Children who are Medically Fragile, Technology Dependent - 0278			
89 IL Admin Code Chapter I Department of Healthcare and Family Services Part 120 Medical Assistance Programs	120.530 - HCBS for Medically Fragile Technology Dependent Children Under the Age of 21	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
Program Instruction Manuals		The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

Illinois Supportive Living Program - 0326			
89 IL Admin Code Chapter 1 Department of Healthcare and Family Services Part 146 Specialized Healthcare Delivery System	146.200 General Description	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter 1 Department of Healthcare and Family Services Part 146 Specialized Healthcare Delivery System	146.205 Definitions	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter 1 Department of Healthcare and Family Services Part 146 Specialized Healthcare Delivery System	146.210 Structural Requirements,	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

89 IL Admin Code Chapter 1 Department of Healthcare and Family Services Part 146 Specialized Healthcare Delivery System	146.215 Participant Requirements	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter 1 Department of Healthcare and Family Services Part 146 Specialized Healthcare Delivery System	146.220 Resident Participation Requirements	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter 1 Department of Healthcare and Family Services Part 146 Specialized Healthcare Delivery System	146.225 Reimbursement for Medicaid Residents	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

89 IL Admin Code Chapter 1 Department of Healthcare and Family Services Part 146 Specialized Healthcare Delivery System	146.230 Services	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter 1 Department of Healthcare and Family Services Part 146 Specialized Healthcare Delivery System	146.235 Staffing	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter 1 Department of Healthcare and Family Services Part 146 Specialized Healthcare Delivery System	146.240 Resident Contract	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

89 IL Admin Code Chapter I Department of Healthcare and Family Services Part 146 Specialized Healthcare Delivery System	146.248 Assessment and Service Plan and Quarterly Evaluation	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter 1 Department of Healthcare and Family Services Part 146 Specialized Healthcare Delivery System	146.250 Resident Rights	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
89 IL Admin Code Chapter 1 Department of Healthcare and Family Services Part 146 Specialized Healthcare Delivery System	146.265 Records and Reporting	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

89 IL Admin Code Chapter 1 Department of Healthcare and Family Services Part 146 Specialized Healthcare Delivery System	146.630 Resident Participation	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
Program Instruction Manuals		The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
Request for Proposal Requirements and Forms		The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

WAIVER PROGRAMS OPERATED BY DHS-DDD - HCBS Waiver for Adults with Developmental Disabilities - 0350, Support Waiver for Children and Young Adults with Developmental Disabilities - 0464; Residential Waiver for Children and Young Adults with Developmental Disabilities - 0473			
59 IL Admin Code Chapter I Department of Human Services Part 115 Standards and Licensure Requirements for Community Integrated Living Arrangements	115.00 through 115.120 - General Provisions	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
59 IL Admin Code Chapter I Department of Human Services Part 115 Standards and Licensure Requirements for Community Integrated Living Arrangements	115.200 through 115.250 - Service Requirements	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
59 IL Admin Code Chapter I Department of Human Services Part 115 Standards and Licensure Requirements for Community Integrated Living Arrangements	115.300 through 115.330 General Agency Requirements	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
59 IL Admin Code Chapter I Department of Human Services Part 115 Standards and Licensure Requirements for Community Integrated Living Arrangements	115.500 through 115.710 Host Family Living Arrangements	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

59 IL Admin Code Chapter I Department of Human Services Part 116 Administration of Medication in Community Settings	116.10 - 116.110 Administration of Medication in Community Settings	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
59 IL Admin Code Chapter I Department of Human Services Part 117 Family Assistance and Home-Based Support Programs for Personal with Mental Disabilities	117.100 through 117.145 General Provisions	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
59 IL Admin Code Chapter I Department of Human Services Part 117 Family Assistance and Home-Based Support Programs for Personal with Mental Disabilities	117.200 through 117.240 Home Based Support Services Program	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
59 IL Admin Code Chapter I Department of Human Services Part 117 Family Assistance and Home-Based Support Programs for Personal with Mental Disabilities	117.300 through 117.350 Family Assistance Program	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

59 IL Admin Code Chapter I Department of Human Services Part 119 Minimum Standards for Certification of Developmental Training Programs	119.100 through 119.120 General Provisions	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
59 IL Admin Code Chapter I Department of Human Services Part 119 Minimum Standards for Certification of Developmental Training Programs	119.200 through 119.270 Program Requirements	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
59 IL Admin Code Chapter I Department of Human Services Part 119 Minimum Standards for Certification of Developmental Training Programs	119.300 through 119.330 Certification Requirements	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
59 IL Admin Code Chapter I Department of Human Services Part 120 Medicaid Home and Community-Based Services Waiver Program for Individuals with Developmental Disabilities	120.10 through 120.50 General Provisions	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

59 IL Admin Code Chapter I Department of Human Services Part 120 Medicaid Home and Community-Based Services Waiver Program for Individuals with Developmental Disabilities	120.70 through 120.120 System Components	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
59 IL Admin Code Chapter I Department of Human Services Part 120 Medicaid Home and Community-Based Services Waiver Program for Individuals with Developmental Disabilities	120.100 through 120.120 Individual Rights and Responsibilities	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
Program Instruction Manuals		The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
Request for Proposal Requirements and Forms		The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

DEFINITIONS - The following terms, as defined by federal guidance will be incorporated in Illinois' HCBS rules, regulations, policies and procedures. These terms are included here to better inform stakeholders of key components of the new CMS rules of which service settings must comply. Additional terms may be modified or added to this list.

Word to be Defined	Site Federal Rule Definition	Action Steps	Target Completion Date
Conflict of Interest Standards	The State must define conflict of interest standards that ensure the independence of individual and agency agents who conduct (whether as a service or an administrative activity) the independent evaluation of eligibility for State plan HCBS, or who are responsible for the development of the service plan. The conflict of interest standards apply to all individuals and entities, public or private. At a minimum, these agents must not be any of the following: (1) Related by blood or marriage to the individual, or to any paid caregiver of the individual; (2) Financially responsible for the individual; (3) Empowered to make financial or health-related decisions on behalf of the individual; (4) Holding financial interest, as defined in 411.354 of this Chapter, in any entity that is paid to provide care for the individual; (5) Providers of State plan HCBS for the individual, or those who have an interest in or are employed by a provider of State plan HCBS for the individual, except when the State demonstrates that the only willing and qualified agent to perform independent assessments and develop person-centered service plans in a geographic area also provides HCBS, and the State devises conflict of interest protections including separation of agent and provider functions within provider entities, which are described in the State plan for medical assistance and approved by the Secretary, and individuals are provided with a clear and accessible alternative dispute resolution process.	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

Heightened Scrutiny	All settings that fall into the category of Settings that are not Home and Community-Based at 441.301(5) (i) through (v) will be presumed to be a setting that has the qualities of an institution unless the Secretary determines through heightened scrutiny, based on information presented by the State or other parties, that the setting does not have the qualities of an institution and that the setting does have the qualities of home and community-based settings.	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
Individual's Representative	441.735 Definition of Individual's representative - The term individual's representative means, with respect to an individual being evaluated for, assessed regarding, or receiving State Plan HCBS, the following: (a) the individual's legal guardian or other person who is authorized under State law to represent the individual for the purpose of making decisions related to the person's care or well-being. In instances where state law confers decision-making authority to the individual representative, the individual will lead the service planning process to the extent possible. (b) Any other person who is authorized under 435.923 of this Chapter, or under the policy of the State Medicaid Agency to represent the individual, including but not limited to, a parent, a family member, or an advocate for the individual; (c) When the State authorizes representative in accordance with paragraph (b) of this section, the State must have policies describing the process for authorization; the extent of decision-making authorized; and safeguards to ensure that the representative uses substituted judgment on behalf of the individual. State policies must address exceptions to using substituted judgment when the individual's wishes cannot be ascertained or when the individual's wishes would result in substantial harm to the individual. States may not refuse the authorized representative that the individual chooses, unless in the process of applying the requirements for authorization, the State discovers and can document evidence that the representative is not acting in accordance with these policies or cannot perform	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

	the required functions. States must continue to meet the requirements regarding the person-centered planning process at 441.725 of this Chapter.		
Legally Enforceable Lease/Residency Agreement	<p>In a provider-owned or controlled residential setting, in addition to the qualities at 441.301(c)(4)(i) through (v), the following additional conditions must be met: (A) The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the State, county, city, or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant, and that it addresses eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law. (B) Each individual has privacy in their sleeping or living unit: (1) Units have entrance doors lockable by the individual, with only appropriate staffing having keys to doors. (2) Individuals sharing units have a choice of roommates in that setting. (3) Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement. (C) Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time. (D) Individuals are able to have visitors of their choosing at any time. (E) The setting is physically accessible to the individual. (F) Any modification of the additional conditions, under 441.301(c)(4) (vi) (A) through (D), must be documented in the person-centered service plan.</p>	<p>The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.</p>	3/17/2017

Person-Centered Plan	441.301(2)(i)-(xiii) - (2) The person-centered service plan must reflect the services and supports that are important for the individual to meet the needs identified through an assessment of functional need, as well as what is important to the individual with regard to preferences for the delivery of such services and supports commensurate with the level of need of the individual, and the scope of services and supports available under the State's 1915(c) HCBS waiver.	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017
Person-Centered Plan Requirementsthe written plan must: (i) Reflect that the setting in which the individual resides is chosen by the individual. The State must ensure that the setting chosen by the individual is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS. (ii) Reflect the individual's strengths and preferences; (iii) Reflect clinical and support needs as identified through an assessment of functional need; (iv) Include individually identified goals and desired outcomes; (v) Reflect the services and supports (paid and unpaid) that will assist the individual to achieve identified goals and the providers of those services and supports, including natural supports. Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of 1915c HCBS waiver services and supports; (vi) Reflect risk factors and measures in place to minimize them, including individualized back-up plans and strategies when needed; (vii) Be understandable to the individual receiving services and supports, and the individuals important in supporting him or her. At a minimum, for the written plan to be understandable, it must be written in plain language and in a manner that is accessible to individuals with disabilities and persons who are limited English proficient with 435.905(b).	The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.	3/17/2017

Home and Community-Based Settings	<p>441.301(4) Home and Community-Based Settings. Home and community-based settings must have all of the following qualities, and such other qualities as the Secretary determines to be appropriate, based on the needs of the individual as indicated in their person-centered service plan: (i) The setting is integrated in and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, to the same degree of access as individuals not receiving HCBS; (ii) The setting is selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting. The setting options are identified and documented in the person-centered service plan and are based on the individual's needs, preferences, and, for residential settings, resources available for room and board; (iii) Ensures an individual's rights of privacy, dignity and respect, and freedom from coercion and restraint; (iv) Optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment and with whom to interact; (v) Facilitates individual choice regarding services and supports, and who provides them; (vi) In a provider-owned or controlled residential setting, in addition to the qualities at 441.301(c)(4)(i) through (v), the following additional conditions must be met: (A) The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the State, county, city, or other designated entity. For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant, and that address eviction processes and appeals comparable to those</p>	<p>The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.</p>	3/17/2017
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	<p>provided under the jurisdiction's landlord tenant law. (B) Each individual has privacy in his/her sleeping or living unit: (1) Units have entrance doors lockable by the individual, with only appropriate staffing having keys to doors. (2) Individuals sharing units have a choice of roommates in that setting. (3) Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement. (C) Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time. (D) Individuals are able to have visitors of their choosing at any time. (E) The setting is physically accessible to the individual. (F) Any modification of the additional conditions, under 441.301(c)(4)(vi)(A) through (D), must be documented in the person-centered service plan.</p>		
Settings that are not Home and Community-Based	<p>441.301(5)(i) through (v) Settings that are not Home and Community-Based - Home and community-based settings do not include the following: (i) A nursing facility; (ii) An institution for mental diseases; (iii) An intermediate care facility for disabilities; (iv) A hospital; (v) Any other locations that have qualities of an institutional setting, as determined by the Secretary. Any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS will be presumed to be a setting that has the qualities of an institution unless the Secretary determines through information presented by the State or other parties, that the setting does not have the qualities of an institution and that the setting does have the qualities of home and community-based settings</p>	<p>The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.</p>	3/17/2017

<p>HCBS Individual's Sleeping or Living Unit</p>	<p>A unit is the individual's private space and dependent on the waiver and the type of unit offered in setting this can either be a living unit or a sleeping unit. Whichever the individual has will be considered the individual's unit. In a provider-owned or controlled residential setting, in addition to the qualities at 441.301(c)(4)(i) through (v), the following additional conditions must be met: (A) The unit or dwelling is a specific physical place that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that tenants have under the landlord/tenant law of the State, county, city, or other designated entity, For settings in which landlord tenant laws do not apply, the State must ensure that a lease, residency agreement or other form of written agreement will be in place for each HCBS participant, and that it addresses eviction processes and appeals comparable to those provided under the jurisdiction's landlord tenant law. (B) Each individual has privacy in his/her sleeping or living unit: (1) Units have entrance doors lockable by the individual, with only appropriate staffing having keys to doors. (2) Individuals sharing units have a choice of roommates in that setting. (3) Individuals have the freedom to furnish and decorate their sleeping or living units within the lease or other agreement. (C) Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time. (D) Individuals are able to have visitors of their choosing at any time. (E) The setting is physically accessible to the individual. (F) Any modification of the additional conditions, under 441.301(c)(4)(vi)(A) through (D), must be documented in the person-centered service plan.</p>	<p>The State will: 1) Review specific definition in relationship to Rule for need to amend; 2) Develop internal agency group to draft revisions based on Rule and site visits; 3) Solicit input from stakeholders; 4) Determine if legislative action is required; 5) Proceed as appropriate to make required revisions; 6) Implement revisions.</p>	<p>3/17/2017</p>
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Appendix B - UIS Residential Settings Report**Assessment of Illinois Home and Community Based Services
Agencies Providing Residential Services**

Developed to assist the Illinois Statewide Transition Plan

Conducted by the Survey Research Office, Center for State Policy & Leadership, University
of Illinois Springfield

Draft report issued on January 22, 2015

Introduction

The purpose of this study is to examine the policies, procedures, and activities of residential settings for Home or Community Based Service waivers. In order to accomplish this, the UIS Survey Research Office, Center for State Policy & Leadership, used a multi-mode methodology in order to allow agencies and settings to self-report on the types of policies and procedures in place throughout settings in Illinois. This report contains four chapters in addition to this introduction.

1. **Scope of Project** - This section provides a brief introduction to the Centers for Medicare and Medicaid Services' (CMS) final rule relating to Home and Community Based Services (HCBS) for Medicaid-funded long term services and supports provided in residential and non-residential home and community-based settings.
2. **Summary of Results** - The purpose of this section is to summarize the results of the two surveys as well as provide an overview of the “Level of Autonomy Score” and the “Frequency of Independent Behaviors Score.” These scores are the numerical values that will be used to identify the key areas of the Illinois Statewide Transition Plan. This section contains four subsections:
 - a. Results from the Agency-Specific Surveys
 - b. Characteristics of the Residential Settings
 - c. Individuals' Access to the Community in Residential Settings
 - d. Individuals' Personal Choice in Care Options in Residential Settings.

This section also provides direction for the next steps in this process.

3. **Methodology** - This section provides a detailed analysis of the methodological design of this project. There were systematic decisions on how to assess all aspects of the settings from engagement with the community, transportation opportunities, residential/room accommodations, visiting hours, meal options, and personal autonomy and choice in care options. A detailed discussion of these decisions and the methodology employed by UIS researchers is provided in the methodology section.
4. **Survey Report** - This is a topline report which includes complete question wording and the frequency of responses to each of the answer categories.

Scope of Project

The Centers for Medicare and Medicaid Services (CMS) published its final rule relating to Home and Community Based Services (HCBS) for Medicaid-funded long term services and supports provided in residential and non-residential home and community-based settings. The final rule took effect on March 17, 2014. According to this rule, states are required to submit transition plans to CMS within one year of the effective date indicating how they intend to comply with the new requirements within a reasonable time period.

In an effort to follow the CMS final rule guidance, the Illinois Department of Healthcare and Family Services, along with the Department of Human Services and the Department on Aging, developed several surveys with assistance of researchers from the UIS Survey Research Office in order to assess the State's current compliance with the new regulations specific to the residential and non-residential settings requirements. This report deals specifically with residential settings offered through HCBS waivers. A report discussing non-residential settings will be provided at a later date.

The following Illinois HCBS waivers are included in this analysis:

- Children and Young Adults with Developmental Disabilities
- Children that are Technology Dependent/Medically Fragile
- Persons with Disabilities
- Persons with Brain Injuries (BI)
- Adults with Developmental Disabilities
- Persons who are Elderly
- Persons with HIV or AIDs
- Supportive Living Facilities

The following types of settings are not included in this classification:

- Hospitals
- Institutions for mental diseases
- An *intermediate* care facility for individuals with intellectual disabilities
- Nursing facilities
- Mental health or DASA residential sites
- Residences for private pay residents only
- Individuals receiving care in their private residences/family homes

This report provides the results of the examination of residential settings for Illinois HCBS waivers.

Summary of Results

The results chapter contains four main sections: Results from the Agency-Specific Surveys, Characteristics of the Residential Settings, Individuals' Access to the Community in Residential Settings, and Individuals' Personal Choice in Care Options in Residential Settings. This executive summary provides an overview of each of the sections as well as a synopsis of the findings. It also provides an overview of the "Level of Autonomy Score" and a "Frequency of Independent Behaviors Score." These scores are the numerical values that will be used to identify the next steps as part of the Illinois Statewide Transition Plan. This section also provides direction for the next steps in this process

Results from the Agency-Specific Surveys

The main survey required from each agency which operates at least one residential setting in Illinois was titled the "Agency-specific survey." Agencies were able to complete this survey online, paper copies sent via U.S. mail, or over the phone with trained SRO interviewers. Of the 256 agencies identified as operating at least one residential setting for Illinois waiver HCBS participants, 244 completed the agency-specific form. This resulted in a 95 percent completion rate among all 256 agencies. The agencies that did not complete the agency-specific form will be contacted by their corresponding state agency in early 2015 in order to assess whether or not these agencies operate residential settings in Illinois. Those that do will be required to complete the agency-specific survey with an individual from the corresponding state agency (Illinois Department of Healthcare and Family Services, the Department of Human Services, or the Department on Aging).

There are three main purposes of the agency-specific survey:

- 1) Determine the number of residential settings in Illinois for HCBS waivers;
- 2) Identify the agencies that have agency-wide policies and procedures that regulate various aspects of the daily operations of their settings;
- 3) Understand the legal policies and restrictions that govern the residential settings.

The main findings of the agency-specific survey are listed below:

- There are currently 1659 residential settings in Illinois.
- The majority of agencies have agency-wide policies that apply to the setting(s) regarding two issues: (a) the living arrangements of the individuals residing at the setting and (b) visitation procedures.
- The majority of agencies do not have agency-wide policies that apply to the setting(s) for the following: (a) limiting individuals' access to food, (b) limit visiting hours, (c) disallowing individuals from engaging in activities, (d) limit individual access to personal funds/resources, (e) disallow individuals from engaging in community activities, (f) limit employment opportunities. For the frequency of responses to these questions, please see the topline report at the end of this report.
- The majority of agencies report that state, county, or city landlord/tenant laws apply to their settings.
- Slightly more than half of agencies have individual residential/service contracts for the individuals living at the setting while 42.9% of the agencies have blanket residential/service contracts.
- Forty-four percent of agencies do not provide units or dwellings that can be owned, rented or occupied under a legally enforceable agreement by the individual receiving services.

Characteristics of the Residential Settings

The setting-specific survey completed by 1659 residential settings allows researchers to gain unique insight into the demographic characteristics of the residential settings. The demographic section provides three important pieces of information.

- 1) The number of individuals (both Illinois HCBS waivers and others) at each residential setting.
- 2) The physical location and type of building of each setting
- 3) The controlling entity for each of the settings

Number of individuals

The mean number of individuals supported at each setting is 8.22, with the largest setting supporting 150 individuals. It is important to note that six settings reported that they are not currently supporting any Illinois HCBS waiver participants.

Physical location and type of building

- Sixteen settings (1%) report that they are “physically connected to a hospital, nursing facility, institution for mental disease, or an intermediate care facility for individuals with intellectual disabilities.”
- Fifty-eight (3.5%) report that while they are not physically connected, they are on the grounds or adjacent to these types of facilities.
- The majority (95.5%) report that they are not physically connect nor adjacent to these type of facilities.

When we examine types of settings, we find that the majority of respondents are Community Integrated Living Arrangements (CILAs). Eighty-nine percent of respondents report that CILA best describes their setting. The table below presents the percent of respondents from each of the categories.

Table 1. Types of settings

	Percent (<i>n</i>)
Community Integrated Living Arrangement (CILA)	89% (1476)
Supportive Living Facility (SLF)	6.2% (103)
Community Living Facility	2.2% (37)
Child Group Home	1.7% (28)
Comprehensive Care in Residential Settings	0.2% (4)
Supported Residential	0.2% (4)
Site-based Permanent Supported/Supportive Housing	0.1% (1)
Other	0.3% (5)

When asked to describe this setting as located in a rural area (located outside of a metropolitan area), located in a suburban area, or located in an urban area, half of respondents described their setting as being located in a suburban area (50.6%). Thirty-one percent reported that their setting was located in a rural area (31.0%) and 18.4 percent reported that their setting was located in an urban area.

When asked to describe the setting, slightly more than half of the settings are single housing units or apartments (50.7%) followed by group housing units (33.5%). Table 2 provides the complete list.

Table 2. Physical description of settings

	Percent (<i>n</i>)
A single housing unit or apartment	54.5% (904)
A group housing unit	36.0% (597)
An apartment building	8.0% (132)
Multiple settings co-located	1.1% (19)
A residential school	0.1% (1)
A gated/secured community	0.1% (1)

Controlling Entity

In addition, when asked what entity or entities control(s) the policies or procedures for the setting, 88.2 percent report that it is the parent agency or organization. Thirty-six report that the landlord controls the policies or procedures (2.2%), followed by private citizen or family (1.9%), the individual setting (1.6%) or a subsidiary or foundation (0.4%).

Finally, settings were told to identify all of the state agencies from which they receive funding for their services. As seen in the table below, the Illinois Department of Human Services is the largest funder for services.

State Agency Funding Services

	Percent (<i>n</i>)
Illinois Department of Human Services	90.7% (1505)
Illinois Department of Healthcare and Family Services	21.0% (349)
Illinois Department on Aging	1.9% (31)

The final two results sections discuss the results of the setting-specific survey. The setting-specific survey deals with all aspects of the residential settings. In order to reduce the complexity of this instrument, we have categorized these into two factors: Individual's Access to the Community in Residential Settings and Individuals' Personal Autonomy and Choice in Care Options in Residential Settings. Each of these sections has the following subsections.

Individuals' Access to the Community in Residential Settings

- Community Engagement
- Transportation Opportunities

Individuals' Personal Choice in Care Options in Residential Settings

- Individual Care Plans
- Dining/Food Accommodations
- Setting Accommodations

Each of settings receives two scores within each of the five subsections: a "Level of Autonomy Score" and a "Frequency of Independent Behaviors Score." These scores measure related but unique concepts. The "Level of

Autonomy Score” measures what level of autonomy or personal freedom individuals experience based on the policies of each residential setting. The “Frequency of Independent Behaviors Score” measures how often individuals engage in these autonomous behaviors. These scores are calculated similarly among all of the five subsections.

“Level of Autonomy Score”- This score is calculated using items on a five-point Likert scale ranging from “Strongly Agree (5), Somewhat Agree (4), Neither Agree nor Disagree (3), Somewhat Disagree (2), Strongly Agree (1).” Settings were asked to report their level of agreement on a variety of different items measuring each of the five subsections. For example, one of the items measuring community engagement using the Likert scale asked respondents their level of agreement with the following statement: *Individuals are given easy access to the community outside of the setting.* While each of the subsections may have a different number of items measuring the concept, the “Level of Autonomy Scores” are standardized.

The scores for each of the subsections range from 1 to 5, where 1 indicates the lowest level of autonomy and 5 indicates the highest level of autonomy. The table below provides the mean “Level of Autonomy Score” for each of the subsections with the standard deviations in parentheses.

Table 3. Level of Autonomy Scores

	Level of Autonomy Score
Community Engagement	4.45 (.60)
Transportation Opportunities	3.77 (.50)
Individual Care Plans	3.84 (.53)
Dining/Food Accommodations	3.46 (.72)
Setting Accommodations	4.77 (.28)

As seen in the table above, all of the “Level of Autonomy Scores” range between the neutral category (3: Neither Agree nor Disagree”) and the strong agreement category (5: “Strongly Agree”). Overall, this indicates a high level of autonomy in each of the five subsections. Setting Accommodations has the highest “Level of Autonomy Score” while Dining/Food Accommodations has the lowest “Level of Autonomy Score.” To find a detailed discussion of the items that constructed each of these scores, please see the corresponding section in the following pages.

“Frequency of Independent Behaviors Score”- This score is calculated using a four-point frequency measure ranging from “All of the time” (4), “Most of the time” (3), “Some of the time” (2), “Never” (1). Settings were asked to report how often a variety of different behaviors occurs for each of the five subsections. For example, one of the items measuring individual care plans using the frequency scale asks respondents to report the frequency of the following item: *Individuals complaints are addressed in a timely manner.*

The scores for each of the subsections range from 1 to 4, where 1 indicates the lowest frequency amount and 4 indicates the highest frequency amount. The table below provides the mean “Frequency of Independent Behaviors Score” for each of the subsections with the standard deviations in parentheses.

Table 4. Frequency of Independent Behaviors Score

	Frequency of Independent Behaviors Score
Community Engagement	2.95 (.58)
Transportation Opportunities	3.25 (.56)
Individual Care Plans	3.35 (.33)
Dining/Food Accommodations	3.12 (.43)
Setting Accommodations	3.19 (.40)

As seen in the table above, all of the “Frequency of Independent Behaviors Scores” range between “Some of the Time” (2) and “All of the Time” (4). Individual Care Plans has the highest “Frequency of Independent Behaviors Score” at 3.35. This indicates that when it comes to individuals’ care plans, the majority of individuals are able to assert a high level of independent behavior. The lowest “Frequency of Independent Behaviors Score” is Community Engagement. To find a detailed discussion of the items that constructed each of these scores, please see the corresponding section in the following pages.

The following pages discuss the five subsections of the results section. Each of the sections provides an overview of the findings (bullet points), and detailed descriptions of both the “Level of Autonomy Score” and the “Frequency of Independent Behaviors Score.”

Individuals’ Access to the Community in Residential Settings

This results section is concerned with the policies and procedures in place that allow individual residents to be able to access the external community, outside of the residential setting. This section contains two subsections: Community Engagement and Transportation Opportunities.

Community Engagement

- Overall, the results on the level of community engagement within the residential settings are mixed. While settings report the second highest autonomy score on community engagement (4.45), they also report the lowest frequency of behaviors score. The latter may be due to the how often individuals within the setting pursue both competitive employment opportunities and noncompetitive employment opportunities.
- When respondents were asked “How often, if at all, do individuals participate in community activities while residing at the setting,” the majority of respondents report that individuals participate in these activities regularly with 87.7 percent of settings reporting this. Twelve percent of respondents report that the individuals participate occasionally and less than one percent (0.4%) report that individuals participate in community activities not often at all.
- The overall “Level of Autonomy Score” for community engagement is 4.45 (out of 5); The “Frequency of Independent Behaviors Score” for community engagement is 2.95 (out of 4).

The overall “Level of Autonomy Score” for community engagement is 4.45, which indicates a high level of autonomy for residents in terms of their engagement in the community. When we examine the six items that constructed this score, we find slight differences among the different measures. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates a low level of autonomy). The item that had the highest percent of respondents reporting that a low autonomy score is “Individuals are able to come and go as they please.”

Table 5. Items of “Level of Autonomy Score”

	Percent reporting lowest rating of autonomy
Individuals are able to come and go as they please.	14.2%
Interested individuals are given the resources on how to obtain employment.	6.2%
Individuals know where to find information on community activities.	4.0%
Individuals receive personal services (e.g., haircuts) in the community outside of the setting.	1.5%
Individuals are given easy access to the community outside of the setting.	0.8%
Individuals receive professional services (e.g., dental care) in the community outside of the setting.	0.6%

The “Frequency of Independent Behaviors Score” was constructed using five items listed in the table below. The overall score for community engagement is 2.95, which indicates the lowest level of the frequency of independent behaviors. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the survey response of “never,” the lowest frequency score). As you can see in the table, the item that had the highest percent of respondents reporting a low frequency score is “individuals pursue competitive employment opportunities” with more than one-fourth of settings report that this never occurs. In addition, 15.1 percent of settings report that individuals never pursue other employment opportunities (both paid and volunteer).

Table 6. Items of “Frequency of Independent Behaviors Score”

	Percent reporting lowest level of frequency
Individuals pursue competitive employment opportunities.	27.3%
Individuals pursue other employment opportunities (both paid and volunteer).	15.1%
Individuals talk about activities occurring outside of the setting.	2.6%
There is a record of the individual residents who attend each community activity event.	1.2%
Individuals participate in personal, social, and family events.	0.1%

Transportation Opportunities

- Overall, while settings report that the individuals engage in independent behaviors with regards to transportation opportunities quite often, it also appears that the level of autonomy associated with transportation is at a moderate level (ranging between neutral and somewhat agree).
- While 97.9 percent of the settings report that their setting is near other private residences and 76.6 percent report that their setting is near retail businesses, providing opportunities for transportation is still an important service provided by these settings. Therefore, 99.3 percent of settings report that they offer transportation opportunities. Twelve settings report that they do not offer any transportation opportunities.
- The overall “Level of Autonomy Score” for transportation opportunities is 3.77; the “Frequency of Independent Behaviors Score” for transportation opportunities is 3.25.

The overall “Level of Autonomy Score” for transportation opportunities is 3.77, which indicates a moderate level of autonomy for residents in terms of their transportation opportunities. When we examine the seven items that constructed this score, we find slight differences among the items. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates a low level of autonomy). As you see in the table, the item that had the highest percent of respondents reporting a low autonomy score is “a transportation schedule is posted in a common area.”

Table 7. Items of “Level of Autonomy Score”

	Percent reporting lowest rating of autonomy
A transportation schedule is posted in a common area.	59.9%
Individuals cannot only enter/exit the setting from designated entrances/exits.	36.3%
Individuals do not have to follow curfews or other requirements for a scheduled return to the setting.	14.6%
There are public transportation opportunities available to individuals in the setting.	11.0%
Transportation opportunities are not limited for individuals.	4.3%
The setting provides transportation opportunities to individuals outside of regularly scheduled options.	1.1%
The setting provides regularly scheduled transportation opportunities to individuals.	0.4%
Individuals feel confident using the transportation opportunities provided by the setting.	0.3%

The “Frequency of Independent Behaviors Score” was constructed using three items listed in the table below. The overall score for transportation opportunities is 3.25, which indicates a high level of the frequency of independent behaviors in terms of transportation opportunities. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the survey response of “never,” the lowest frequency score). As you can see in the table, the item that had the highest percent of respondents reporting a low frequency score is “individuals are informed/educated on how to use public transportation.”

Table 8. Items of “Frequency of Independent Behaviors Score”

	Percent reporting lowest level of frequency
Individuals are informed/educated on how to use public transportation.	14.1%
Individuals use the transportation opportunities provided by the setting.	0.8%
Individuals know how to contact a staff member about transportation opportunities.	3.3%

Individuals' Personal Choice in Care Options in Residential Settings

This results section is concerned about the level of personal choice individual residents have while residing at the settings. This includes their individual care plans, their living arrangements, their sense of individuality, their dining arrangements, and their interactions with visitors and staff members. This section contains three subsections: Individual Care Plans, Dining/Food Accommodations, and Setting Accommodations

Individual Care Plans

- A vital component of the new federal regulations is that individuals at residential settings have flexibility and freedom in developing their individual care plans. The results of this survey indicate that the frequency of independent behaviors associated with individual care plans is at a high level.
- The majority of the residential settings that responded to this survey report that while individuals have a lot of choice in the type of care or assistance they receive or from whom, they are not in complete control. Eighty-eight percent of residential settings report this to be the case while 8.6 percent report that individuals have complete control and 3.8 percent report that individuals have little choice or control.
- Almost all of the settings (98%) report that the average individual at their setting has been asked about their goals and aspirations in the past 12 months and 79.5 percent report that individuals make changes to their plan of care “as needed or as requested.”
- The overall “Level of Autonomy Score” for individual care plans is 3.84, the “Frequency of Independent Behaviors Score” for individual care plans is 3.35.

The overall “Level of Autonomy Score” for individual care plans is 3.84, which indicates a moderate level of autonomy for residents in terms of their individual care plans. When we examine the six items that constructed this score, we find slight differences among the measures. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the lowest level of autonomy). The item that had the highest percent of respondents reporting the lowest autonomy score is “individual requests regarding their care are forward to an independent/non-setting based case manager”

Table 9. Items of “Level of Autonomy Score”

	Percent reporting lowest rating of autonomy
Individual requests regarding their care are forwarded to an independent/non-setting based case manager.	16.8%
Information on how to file a complaint is easily accessible to individuals.	4.1%
Individuals have a choice of which provider staff delivers care/support.	2.6%
Individual schedules for PT, OT, medication, diet, or other care options are NOT posted in common areas (i.e., hallways).	2.4%
Individuals know how make changes to their plans of care.	1.6%
Individuals feel comfortable expressing concerns regarding their care.	0.6%

The “Frequency of Independent Behaviors Score” was constructed using eight items listed in the table below. The overall score for individual care plan is 3.35, which indicates the highest level of the frequency of independent behaviors in terms of individual care planning. The table below presents the percent of respondents who self-

reported a “1” on this item (which indicates the survey response of “never,” the lowest frequency score). The item that had the highest percent of respondents reporting a low frequency score is “Staff members do not discuss individuals with other staff members in public space.” 7 percent of settings report that this never happens.

Table 10. Items of “Frequency of Independent Behaviors Score”

	Percent reporting lowest level of frequency
Staff members do not discuss individuals with other staff members in public spaces.	7.0%
Individuals make changes to their plan of care as needed.	2.0%
When needed, individuals know how to request a new/additional service.	2.0%
Individuals with concerns, discuss the concerns with the setting staff.	0.9%
Individuals provide input into their daily schedules.	0.5%
Individual complaints are addressed in a timely manner.	0.1%
When an individual files a complaint, it is considered confidential.	0.1%
Individuals have the opportunity to express their level of satisfaction with the services they are receiving.	0.0%

Dining/Food Accommodations

- One way that individuals are able to express their own personal choice is in their dining and meal decisions. According to the survey results, current setting accommodations do not allow a lot of freedom and flexibility in regards to dining and food accommodations. One of the major restrictions is where individuals are allowed to eat with a significant number of settings reporting that individuals are not allowed to eat in their units nor eat outside of common dining areas.
- Slightly more than half of the settings (52.3%) report that individuals have a lot of choice when it comes to their dining and meal decisions. Forty-seven percent of settings report that individuals have some choice when it comes to these decisions and less than one percent (0.2%) report that individuals have no choice at all.
- The overall “Level of Autonomy Score” for dining/food accommodations is 3.46; the “Frequency of Independent Behaviors Score” for dining and food accommodations is 3.12.

The overall “Level of Autonomy Score” for dining/food accommodations is 3.46, which is the lowest score among all of the subsections. When we examine the five items that constructed this score, we find differences among the items. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates a low level of autonomy). The item that had the highest percent of respondents reporting a low autonomy score is “individuals are able to eat in their units.”

Table 11. Items of “Level of Autonomy Score”

	Percent reporting lowest rating of autonomy
Individuals are able to eat in their units.	18.2%
Individuals are able to set their own dining/meal-time schedule.	5.5%
Individuals are able to eat in places other than the common dining areas.	5.4%
Individuals do not have assigned seating during meal-times.	1.5%
Individuals are able to eat at non-designated meal-times.	0.9%

The “Frequency of Independent Behaviors Score” was constructed using four items listed in the table below. The overall score for dining and food accommodations is 3.12, which indicates a lower level of the frequency of independent behaviors in terms of dining and food accommodations. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the survey response of “never,” the lowest frequency score). The item that had the highest percent of respondents reporting a low frequency score is “individuals eat in places other than common dining areas.”

Table 12. Items of “Frequency of Independent Behaviors Score”

	Percent reporting lowest level of frequency
Individuals eat in places other than common dining areas.	16.0%
There is more than one meal option during meal-times.	1.4%
Between designated meal-times, the setting provides other food or refreshments.	1.2%
Individuals engage with others during meal-times.	0.9%

Setting Accommodations

- According to the survey results, individuals have a lot of autonomy when it comes to their setting accommodations as well as demonstrate frequently independent behaviors.
- More than half of the settings report that individuals have a lot of freedom to move inside/outside of the setting (57.3%), while 42.24 percent report that they have some freedom and less than one percent reporting that they have no freedom at all. In addition, 65 percent of the settings report that individuals residents have a lot of privacy while at the setting.
- The overall “Level of Autonomy Score” for setting accommodations is 4.77; the “Frequency of Independent Behaviors Score” is 3.19.

The overall “Level of Autonomy Score” for setting accommodations is 4.77. This score is the highest of all of the subsections indicating a very high level of autonomy for individuals in terms of their setting accommodations. When we examine the twelve items that constructed this score, we find slight differences among the items. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the lowest level of autonomy). The item that had the highest percent of respondents reporting the lowest autonomy score is “individuals are able to lock the door to their units.”

Table 13. Items of “Level of Autonomy Score”

	Percent
Individuals are able to lock the door to their units.	46.6%
Individuals are allowed to have their own checking and/or savings account.	5.8%
Individuals are able to furnish and decorate their units to their own preferences.	3.5%
Individuals have access to cell phones, computers, and other mobile technological devices in common areas.	3.0%
Visitors are allowed to visit individuals in the setting outside of regularly scheduled visiting hours.	1.6%
Individuals are allowed to own cell phones, computers, and other mobile technological devices.	1.4%
Individuals have access to do their own laundry.	1.2%
Visitors are free to move about public areas within the setting.	0.7%
Individuals have access to a kitchen setting.	0.6%
Individuals have access to a television in common areas.	0.5%
Individuals are allowed to receive visitors at this setting.	0.2%
Individuals are able to have their own sense of style.	0.0%

The “Frequency of Independent Behaviors Score” was constructed using twelve items listed in the table below. The overall score is 3.19, which indicates a moderate level of the frequency of independent behaviors in terms for setting accommodations. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the survey response of “never,” the lowest frequency score). The item that had the highest percent of respondents reporting a low frequency score is “married couples have the option to share a unit.”

Table 14. Items of “Frequency of Independent Behaviors Score”

	Percent reporting lowest level of frequency
Married couples have the option to share a unit.	25.3%
Individuals and their visitors do not have to follow the visiting hour schedules	25.1%
Individuals have the option to live in private units.	14.9%
If sharing a room, individuals get to choose a roommate.	13.2%
Setting providers do not maintain control over the individual’s finances.	12.6%
Individuals with roommates discuss their living situation with staff or counselors.	7.8%
Individuals are not assigned a roommate by staff.	1.7%
Staff members assist the individuals who need help getting dressed, at a time designated by the individual.	1.5%
Staff members do not have difficulty getting along with individuals at the setting.	0.7%
Staff members knock before entering individuals units.	0.1%
Individuals choose their daily clothing.	0.1%
Individuals are clean and well-groomed.	0.1%

The Next Steps in the Illinois Statewide Transition Plan

One of the main purposes of these surveys is to help the Illinois Departments of Healthcare and Family Services, Human Services, and Aging develop the statewide transition plan as dictated by the Centers for Medicare and Medicaid Services (CMS) final rule relating to Home and Community Based Services (HCBS) for Medicaid-funded long term services and supports. The UIS Survey Research Office suggests the following steps in order to follow these federal guidelines.

1. Of the 256 agencies identified as operating at least one residential setting for Illinois waiver HCBS participants, 244 completed the agency-specific form. The agencies that did not complete the agency-specific form should be contacted by their corresponding state agency in early 2015 in order to assess whether or not these agencies operate residential settings in Illinois. Those that do will be required to complete the agency-specific survey with an individual from the corresponding state agency (Illinois Departments of Healthcare and Family Services, Human Services, or Aging).
2. Representatives designated by the Illinois Departments of Healthcare and Family Services, Human Services, and Aging should conduct site visits at all of the 16 settings that reported that they were physically connected to a hospital, nursing facility, institution for mental diseases, or an intermediate care facility for individuals with intellectual disabilities.
3. Representatives designated by the Illinois Departments of Healthcare and Family Services, Human Services, and Aging should conduct site visits of the residential settings that scored the lowest on either the “Level of Autonomy” and “Frequency of Independent Behavior” scores. In order to be able to compare the different scores (which were computed using a different number of items), the scores were standardized with the mean score for each of the items being a “0,” and the standard deviation being +/- 1. Therefore, we suggest that site visits are conducted at each setting that scored significantly lower than median score on each of the different scores as well as those settings that score significantly lower than 99 percent of the sample on any of the individual score.
4. Representatives designated by the Illinois Departments of Healthcare and Family Services, Human Services, and Aging should conduct site visits of a sample of the residential settings that scored within the mean on the “Level of Autonomy” and within the mean “Frequency of Independent Behavior” scores. Even though steps were taken to lower the likelihood of response bias, it is still possible that bias affected how some agencies responded. People may be inclined, for example, to give the response that they think will make them look good, rather than the one that accurately represents their situation. Consequently, we suggest that site visits be made to no more than 2 percent of the sample as a way to validate the survey results.

Methodology

The HCBS residential survey is actually two surveys: an agency-specific survey and a setting-specific survey. Every agency was required to fill out both an agency-specific residential survey as well as a setting-specific residential survey for each of their residential settings. Settings were able to participate in the surveys via online, mail, and phone.

The Illinois Department of Healthcare and Family Services, along with the Department of Human Services and the Department on Aging provided a list of agencies which operate residential settings offered through HCBS waivers. A total of 256 agencies met these guidelines. Mailing addresses, contact information for the director of each agency, and email addresses were provided by each of the corresponding state agencies. All agencies were contacted at least five times by researchers at the Survey Research Office (SRO).

The first contact to the agencies was through emails from their corresponding state agencies: Illinois Departments of Healthcare and Family Services, Human Services, or Aging. After the email distribution, the same information was sent from the SRO in an introductory letter via U.S. Postal Service on September 26th, 2014. This correspondence discussed the need for Illinois to take inventory of all supportive congregate and/or group residential settings that are not hospitals, nursing homes, IMDs or ICF-DDs and where the HCBS participant and the State, at this time, considers this setting as his/her residence. This letter also informed the agency that they will be receiving information on how to complete a survey for their residential settings from the University of Illinois at Springfield (UIS). In addition, the recipients received specific language explaining that while there are no right or wrong answers to questions, their participation in the survey is mandatory.

The first round of survey instruments was sent to each of the 256 agencies via U.S. Postal Service on October 3rd, 2014. Included in the mailing was an introductory letter to the director of the agency, an agency-specific survey, ten copies of the setting-specific survey, and five business reply envelopes. The agency-specific survey contained an identifying tracking number in order for SRO researchers to keep track of the agencies who had completed the surveys. Individuals were instructed that they could complete the hard copies of the surveys included in the mailing packet or complete the surveys online through provided URLs. If agencies needed additional copies of the setting-specific survey, they were instructed to contact the SRO via email or telephone.

A reminder postcard was sent to all of the agencies on October 13, 2014. This postcard contained the project identification number for each of the agencies as well the URL to complete the surveys online. A second mailing occurred on October 17th, 2014. This mailing included the introductory letter, the agency-specific survey, and five copies of the setting-specific survey. Agencies that had not completed the surveys by November 4, 2014 received phone calls from trained SRO interviewers. These phone calls were placed at different dates and times of the work week in an effort to increase the number of responses. Phone interviews concluded on November 23, 2014. The survey closed on December 15, 2014.

Through these various methods, SRO was able to get information through the survey from 244 of the 256 agencies (95%) that operate residential settings in Illinois. In addition, these agencies are responsible for operating 1659 residential settings in Illinois.

Response bias may occur within surveys that rely on self-assessment, especially in situations in which funding may be in jeopardy. The following steps were taken to mitigate this bias:

1) The instructions attached to both surveys -- agency-specific and setting-specific -- emphasized that the data provided by both the agency and the setting are for informational purposes only and will not be used to assess the federal compliance of either the agency or the setting.

2) The following information was included on every page of the setting-specific survey:

REMINDER: The input you provide will be used to inform the Transition Plan and will NOT be used to evaluate whether the setting is currently in compliance with the new federal requirements. For example, selecting “Never” or “Strongly Disagree” for one of the items does not indicate that you are not in compliance. *Please answer the questions based on what “typically occurs” in the setting.* The emphasis is on what are in the setting’s policies and procedures. It is recognized that individual’s plans of care may dictate certain restrictions that would be documented to cause harm or reflect one’s abilities.

3) The majority of both surveys used Likert scales to effectively evaluate agencies and settings. The Likert technique is one of the most used and most validated survey designs. It involves asking a respondent to indicate how much he/she agrees or disagrees with each of a set of statements. The surveys used a five-point Likert response scale: strongly disagree, disagree, neutral, agree, or strongly agree.

4) Each survey included both positive statements (Individuals have access to a kitchen setting) and negative statements (Individuals do NOT have access to do their own laundry). When a survey or section of a survey contains only positive or only negative items, research shows that this can influence how people respond. A set of items worded only positively (with no negative items mixed in) can induce a positive bias from respondents. They respond by agreeing with those items more than they might if the set also included negatively worded items. The same goes for only framing survey items negatively. Thus, to reduce this bias, the surveys always include a mix of positively and negatively worded items.

5) In addition to the Likert design, the survey included questions on the frequency of certain behaviors, rather than just asking whether the behavior occurs or not. The questions included asking respondents “how often” certain activities occur at the setting. The four-point response categories ranged from “all of the time,” “most of the time,” “some of the time,” and “never.” Including this scale allows individuals to provide more specific and useful information.

The following report is separated into four sections: Results from the Agency-specific Surveys, Demographics of the Residential Settings, Individuals’ Access to the Community in Residential Settings, Individuals’ Personal Autonomy and Choice in Care Options in Residential Settings.

If you have any questions or comments about this report, please contact the Survey Research Office:

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Topline Report

Agency-Specific Surveys

How much, if at all, do you agree with the following statements about your agency? Do you strongly agree, somewhat agree, somewhat disagree, or strongly disagree? If you do not know the answer, please check “Don’t know.”

There are agency-wide policies that apply to the setting(s) regarding visitation procedures.

	Percent (<i>n</i>)
Strongly agree	47.6% (108)
Somewhat agree	28.6% (65)
Somewhat disagree	6.2% (14)
Strongly disagree	14.1% (32)
Don’t know	3.5% (8)

There are agency-wide policies that apply to the setting(s) regarding the living arrangements of the individuals residing at the setting(s).

	Percent (<i>n</i>)
Strongly agree	64.2% (145)
Somewhat agree	23.0% (52)
Somewhat disagree	3.5% (8)
Strongly disagree	5.8% (13)
Don’t know	3.5% (8)

There are agency-wide policies and procedures that limit individuals’ access to food at its setting(s).

	Percent (<i>n</i>)
Strongly agree	3.9% (9)
Somewhat agree	8.7% (20)
Somewhat disagree	12.7% (29)
Strongly disagree	71.6% (164)
Don’t know	3.1% (7)

There are agency-wide policies and procedures that limit visiting hours at its setting(s).

	Percent (<i>n</i>)
Strongly agree	6.6% (15)
Somewhat agree	14.5% (33)
Somewhat disagree	17.5% (40)
Strongly disagree	59.2% (135)
Don’t know	2.2% (5)

There are agency-wide policies and procedures that disallow individuals from engaging in legal activities at its setting(s).

	Percent (<i>n</i>)
Strongly agree	4.4% (10)
Somewhat agree	5.3% (12)
Somewhat disagree	4.4% (10)
Strongly disagree	76.0% (171)
Don't know	9.8% (22)

There are agency-wide policies and procedures that limit individual access to their personal funds/resources at its setting(s).

	Percent (<i>n</i>)
Strongly agree	6.2% (14)
Somewhat agree	13.2% (30)
Somewhat disagree	10.1% (23)
Strongly disagree	68.7% (156)
Don't know	1.8% (4)

There are agency-wide policies and procedures that disallow individuals from engaging in community activities at its setting(s).

	Percent (<i>n</i>)
Strongly agree	0.4% (1)
Somewhat agree	1.3% (3)
Somewhat disagree	3.9% (9)
Strongly disagree	91.7% (21)
Don't know	2.6% (6)

There are agency-wide policies and procedures that limit individual employment opportunities at its setting(s).

	Percent (<i>n</i>)
Strongly agree	2.2% (5)
Somewhat agree	3.9% (9)
Somewhat disagree	6.6% (15)
Strongly disagree	80.8% (185)
Don't know	6.6% (15)

Please answer whether the following apply to all of your settings, some of your settings, none of your settings. If you do not know the answer, please check "Don't know."

State, county, or city landlord/tenant laws apply to your setting(s).

	Percent (<i>n</i>)
Applies to all of our settings	36.4% (82)
Applies to some of our settings	20.9% (47)
Applies to none of our settings	25.3% (57)
Don't know	17.3% (39)

The agency has a blanket residential/service contract for all individuals residing at the setting(s).

	Percent (<i>n</i>)
Applies to all of our settings	42.9% (97)
Applies to some of our settings	7.5% (17)
Applies to none of our settings	41.2% (93)
Don't know	8.4% (19)

The agency has individual residential/service contracts for all individuals residing at the setting(s).

	Percent (<i>n</i>)
Applies to all of our settings	51.3% (116)
Applies to some of our settings	7.1% (16)
Applies to none of our settings	35.8% (81)
Don't know	5.8% (13)

The agency provides units or dwellings that can be owned, rented, or occupied under a legally enforceable agreement by the individual receiving services.

	Percent (<i>n</i>)
Applies to all of our settings	35.0% (79)
Applies to some of our settings	11.9% (27)
Applies to none of our settings	44.2% (100)
Don't know	8.8% (20)

Setting-Specific Survey

How many HCBS or other State-funded approved participants are supported at this location?

	Percent (<i>n</i>)
Less than five	39.8% (662)
Five to 10 participants	51.6% (860)
11-20 participants	2.4% (39)
More than 20 participants	7.0% (103)

Which of the following best describes your setting?

	Percent (<i>n</i>)
Physically connected to a hospital, nursing facility, institution for mental diseases, or an intermediate care facility for individuals with intellectual disabilities.	1.0% (16)
Not physically connected but on the grounds or adjacent to a hospital, nursing facility, institution for mental diseases, or an intermediate care facility for individuals with intellectual disabilities.	3.5% (58)
Not physically connected or adjacent hospital, nursing facility, institution for mental diseases, or an intermediate care facility for individuals with intellectual disabilities.	95.5% (1570)

Please identify all state agencies with whom you may receive funding to provide services for:

	Percent (n)
Illinois Department of Human Services	90.7% (1505)
Illinois Department of Healthcare and Family Services	21.0% (349)
Illinois Department on Aging	1.9% (31)

Which of the following best describes the setting?

	Percent (n)
Community Integrated Living Arrangement (CILA)	89% (1476)
Supportive Living Facility (SLF)	6.2% (103)
Community Living Facility	2.2% (37)
Child Group Home	1.7% (28)
Comprehensive Care in Residential Settings	0.2% (4)
Supported Residential	0.2% (4)
Site-based Permanent Supported/Supportive Housing	0.1% (1)
Other	0.3% (5)

Would you describe this setting as located in a rural area, located in a suburban area, or located in an urban area?

	Percent (n)
Located in a rural area (located outside of a metropolitan area)	31.0% (51)
Located in a suburban area	50.6% (826)
Located in an urban area	18.4% (300)

Please select all of the following that describe this setting:

	Percent (n)
A single housing unit or apartment	54.5% (904)
A group housing unit	36.0% (597)
An apartment building	8.0% (132)
Multiple settings co-located	1.1% (19)
A residential school	0.1% (1)
A gated/secured community	0.1% (1)

What entity/entities control(s) the policies or procedures for this setting?

	Percent (n)
The parent agency/organization	88.2% (1454)
The individual setting	1.6% (27)
A subsidiary or foundation	0.4% (6)
A landlord	2.2% (36)
A private citizen or family	1.9% (31)
Other, please specify:	5.8% (95)

Others mentioned: Agency board of directors, Private citizen, Not for profit, Housing authority.

Community Activities

The first set of questions deal with access to community activities (events occurring external to your setting such as religious services, shopping, employment, or other social/personal/family events outside of the setting). We are interested in how individuals participate in unscheduled and scheduled community activities at your setting.

How often, if at all, do individuals participate in community activities while residing at the setting? Would you say that the majority of individuals participate in these activities regularly, occasionally, or not often at all?

	Percent (<i>n</i>)
Regularly	87.7% (1439)
Occasionally	11.8% (194)
Not often at all	0.4% (7)

Please select whether the following occur all of the time, most of the time, some of the time, or never.

For each community activity, there is a record of the individual residents who attended the event.

	Percent (<i>n</i>)
All of the time	44.7% (733)
Most of the time	40.8% (668)
Some of the time	13.3% (218)
Never	1.2% (20)

Individuals participate in personal, social, and family events (i.e., attend religious services, eat with family).

	Percent (<i>n</i>)
All of the time	55.4% (913)
Most of the time	28.8% (474)
Some of the time	15.7% (259)
Never	0.1% (1)

Individuals pursue competitive employment opportunities.

	Percent (<i>n</i>)
All of the time	13.6% (223)
Most of the time	9.4% (154)
Some of the time	49.8% (818)
Never	27.3% (448)

Individuals pursue other employment opportunities (both paid and volunteer).

	Percent (<i>n</i>)
All of the time	26.8% (441)
Most of the time	22.2% (365)
Some of the time	35.8% (589)
Never	15.1% (248)

Individuals talk about activities occurring outside of the setting.

	Percent (<i>n</i>)
All of the time	56.7% (933)
Most of the time	24.2% (397)
Some of the time	16.5% (272)
Never	2.6% (43)

How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Individuals do NOT know where to find information on community activities.

	Percent (<i>n</i>)
Strongly agree	4.0% (65)
Somewhat agree	14.2% (232)
Neither agree nor disagree	12.3% (202)
Somewhat disagree	30.2% (494)
Strongly disagree	39.3% (644)

Individuals are able to come and go as they please.

	Percent (<i>n</i>)
Strongly agree	22.5% (367)
Somewhat agree	32.5% (530)
Neither agree nor disagree	14.8% (242)
Somewhat disagree	14.6% (238)
Strongly disagree	15.5% (253)

Interested individuals are given the resources on how to obtain employment.

	Percent (<i>n</i>)
Strongly agree	50.0% (818)
Somewhat agree	27.4% (448)
Neither agree nor disagree	11.1% (181)
Somewhat disagree	5.4% (89)
Strongly disagree	6.2% (101)

Individuals are given easy access to the community outside of the setting.

	Percent (<i>n</i>)
Strongly agree	58.2% (954)
Somewhat agree	31.3% (514)
Neither agree nor disagree	6.5% (106)
Somewhat disagree	3.2% (53)
Strongly disagree	0.8% (13)

Individuals do NOT receive any personal services (e.g., haircuts) in the community outside of the setting.

	Percent (<i>n</i>)
Strongly agree	1.5% (25)
Somewhat agree	2.0% (33)
Neither agree nor disagree	0.4% (6)
Somewhat disagree	5.6% (92)
Strongly disagree	90.% (1485)

Individuals do NOT receive any professional services (e.g., dental care) in the community outside of the setting.

	Percent (<i>n</i>)
Strongly agree	0.6% (10)
Somewhat agree	1.6% (26)
Neither agree nor disagree	0.1% (2)
Somewhat disagree	3.4% (56)
Strongly disagree	94.3% (1542)

Setting Accommodations

The next set of questions deal with the accommodations provided by your setting for individuals.

Do individuals at your setting have a lot of choice, some choice, or no choice at all in the initial decision to live at your setting?

	Percent (<i>n</i>)
A lot of choice	65.0% (1058)
Some choice	33.2% (54)
No choice at all	1.8% (29)

When it comes to residential options for an individual living at the setting, would you say that a typical individual has a lot of choice, some choice, or no choice at all?

	Percent (<i>n</i>)
A lot of choice	46.9% (765)
Some choice	52.0% (848)
No choice at all	1.2% (19)

In general, would you say that individual residents have a lot of privacy, some privacy, or no privacy at the setting?

	Percent (<i>n</i>)
A lot of privacy	65.0% (1059)
Some privacy	35.0% (570)
No privacy at all	0.1% (1)

How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Individuals are NOT allowed to receive visitors at this setting.

	Percent (<i>n</i>)
Strongly agree	0.2% (3)
Somewhat agree	0.0% (0)
Neither agree nor disagree	0.2% (4)
Somewhat disagree	1.3% (21)
Strongly disagree	98.3% (1607)

Individuals are able to furnish and decorate their units to their own preferences.

	Percent (<i>n</i>)
Strongly agree	84.9% (1388)
Somewhat agree	10.6% (174)
Neither agree nor disagree	0.4% (6)
Somewhat disagree	0.5% (8)
Strongly disagree	3.5% (58)

Individuals are NOT able to lock the door to their units.

	Percent (<i>n</i>)
Strongly agree	17.1% (279)
Somewhat agree	7.6% (124)
Neither agree nor disagree	8.3% (135)
Somewhat disagree	20.5% (334)
Strongly disagree	46.6% (761)

Visitors are free to move about public areas within the setting (common areas, dining rooms).

	Percent (<i>n</i>)
Strongly agree	84.4% (1380)
Somewhat agree	11.9% (195)
Neither agree nor disagree	2.9% (47)
Somewhat disagree	0.2% (3)
Strongly disagree	0.7% (11)

Visitors are allowed to visit individuals in the setting outside of regularly scheduled visiting hours.

	Percent (<i>n</i>)
Strongly agree	53.8% (874)
Somewhat agree	28.2% (459)
Neither agree nor disagree	12.9% (209)
Somewhat disagree	3.5% (57)
Strongly disagree	1.6% (26)

Please select whether the following occur all of the time, most of the time, some of the time, or never.

Individuals have the option to live in private units.

	Percent (<i>n</i>)
All of the time	47.4% (771)
Most of the time	15.1% (246)
Some of the time	22.5% (366)
Never	14.9% (242)

If sharing a room, individuals get to choose a roommate.

	Percent (<i>n</i>)
All of the time	26.4% (395)
Most of the time	27.6% (412)
Some of the time	32.8% (490)
Never	13.2% (197)

Married couples have the option to share a unit.

	Percent (<i>n</i>)
All of the time	65.7% (1020)
Most of the time	5.2% (80)
Some of the time	3.9% (60)
Never	25.3% (393)

Staff members knock before entering individual units.

	Percent (<i>n</i>)
All of the time	76.3% (1241)
Most of the time	20.5% (333)
Some of the time	3.2% (52)
Never	0.1% (1)

Individuals with roommates discuss their living situation with staff or counselors.

	Percent (<i>n</i>)
All of the time	51.2% (766)
Most of the time	25.4% (380)
Some of the time	15.6% (233)
Never	7.8% (117)

Individuals are assigned a roommate by staff.

	Percent (<i>n</i>)
All of the time	1.7% (26)
Most of the time	9.8% (148)
Some of the time	46.4% (698)
Never	42.0% (631)

Individuals and their visitors follow the visiting hour schedules.

	Percent (<i>n</i>)
All of the time	25.1% (376)
Most of the time	47.9% (718)
Some of the time	5.4% (81)
Never	21.6% (323)

In general, would you say that individuals have a lot of freedom to move inside/outside of the setting, some freedom to move inside/outside of the setting, or no freedom to move inside/outside of the setting?

	Percent (<i>n</i>)
A lot of freedom	57.3% (934)
Some freedom	42.4% (691)
No freedom	0.4% (6)

Next, we are interested in the dining/food accommodations at your setting. When it comes to dining/food options, would you say that a typical individual has a lot of choice, some choice, or no choice at all?

	Percent (<i>n</i>)
A lot of choice	52.3% (850)
Some choice	47.4% (770)
No choice at all	0.2% (4)

Please select whether the following occur all of the time, most of the time, some of the time, or never.

Individuals do NOT engage with others during meal-times.

	Percent (<i>n</i>)
All of the time	0.9% (14)
Most of the time	1.7% (27)
Some of the time	23.9% (387)
Never	73.6% (1192)

There is more than one meal option during meal-times.

	Percent (<i>n</i>)
All of the time	41.3% (671)
Most of the time	19.8% (322)
Some of the time	37.5% (609)
Never	1.4% (23)

Individuals eat in places other than common dining areas.

	Percent (<i>n</i>)
All of the time	8.9% (145)
Most of the time	2.3% (37)
Some of the time	72.8% (1183)
Never	16.0% (260)

Between designated meal-times, the setting provides other food or refreshments.

	Percent (<i>n</i>)
All of the time	79.1% (1288)
Most of the time	17.5% (285)
Some of the time	2.2% (36)
Never	1.2% (19)

How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Individuals are assigned seating during meal-times.

	Percent (<i>n</i>)
Strongly agree	1.5% (25)
Somewhat agree	4.9% (80)
Neither agree nor disagree	9.2% (150)
Somewhat disagree	9.7% (158)
Strongly disagree	74.6% (1215)

Individuals are NOT able to eat at non-designated meal-times.

	Percent (<i>n</i>)
Strongly agree	0.9% (15)
Somewhat agree	3.9% (63)
Neither agree nor disagree	3.2% (52)
Somewhat disagree	23.8% (387)
Strongly disagree	68.2% (1110)

Individuals are able to eat in places other than common dining areas.

	Percent (<i>n</i>)
Strongly agree	28.3% (460)
Somewhat agree	45.4% (739)
Neither agree nor disagree	5.4% (88)
Somewhat disagree	15.5% (253)
Strongly disagree	5.4% (88)

Individuals are NOT allowed to eat in their units.

	Percent (<i>n</i>)
Strongly agree	18.2% (296)
Somewhat agree	26.7% (433)
Neither agree nor disagree	9.5% (154)
Somewhat disagree	18.4% (299)
Strongly disagree	27.1% (440)

Individuals are able to set their own dining/meal-time schedule.

	Percent (<i>n</i>)
Strongly agree	14.6% (238)
Somewhat agree	42.9% (699)
Neither agree nor disagree	16.8% (274)
Somewhat disagree	20.1% (327)
Strongly disagree	5.5% (90)

We are also interested in the transportation opportunities and access at your setting. How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Individuals can only enter/exit the setting from designated entrances/exits.

	Percent (<i>n</i>)
Strongly agree	36.3% (589)
Somewhat agree	11.0% (179)
Neither agree nor disagree	10.1% (164)
Somewhat disagree	5.4% (87)
Strongly disagree	37.1% (602)

There are NO public transportation opportunities available to individuals in the setting.

	Percent (<i>n</i>)
Strongly agree	11.0% (179)
Somewhat agree	15.1% (246)
Neither agree nor disagree	3.3% (54)
Somewhat disagree	28.7% (467)
Strongly disagree	41.9% (681)

The setting provides regularly scheduled transportation opportunities to individuals.

	Percent (<i>n</i>)
Strongly agree	79.6% (1258)
Somewhat agree	16.7% (264)
Neither agree nor disagree	2.3% (37)
Somewhat disagree	0.9% (14)
Strongly disagree	0.4% (7)

The setting provides transportation opportunities to individuals outside of regularly scheduled options.

	Percent (<i>n</i>)
Strongly agree	65.8% (1075)
Somewhat agree	27.4% (447)
Neither agree nor disagree	2.0% (32)
Somewhat disagree	3.7% (61)
Strongly disagree	1.1% (18)

Individuals have to follow curfews or other requirements for a scheduled return to the setting.

	Percent (n)
Strongly agree	14.6% (237)
Somewhat agree	37.4% (608)
Neither agree nor disagree	10.5% (171)
Somewhat disagree	16.2% (263)
Strongly disagree	21.4% (348)

Is your setting near other private residences?

	Percent (n)
Yes	97.9% (1593)
No	2.1% (35)

Are retail businesses near your setting?

	Percent (n)
Yes	76.6% (1246)
No	23.4% (381)

Only answer these questions if your setting provides transportation opportunities to individuals. If your setting does not provide transportation opportunities, please continue to the next page.

Please select whether the following occur all of the time, most of the time, some of the time, or never.

Individuals are informed/educated on how to use public transportation.

	Percent (n)
All of the time	26.7% (428)
Most of the time	29.9% (478)
Some of the time	29.4% (470)
Never	14.1% (225)

Individuals use the transportation opportunities provided by the setting.

	Percent (n)
All of the time	70.7% (1140)
Most of the time	23.7% (382)
Some of the time	4.8% (78)
Never	0.8% (13)

Individuals know how to contact a staff member about transportation opportunities.

	Percent (n)
All of the time	60.8% (978)
Most of the time	26.4% (424)
Some of the time	9.6% (154)
Never	3.3% (53)

How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Transportation opportunities are limited for individuals.

	Percent (<i>n</i>)
Strongly agree	4.3% (70)
Somewhat agree	20.5% (331)
Neither agree nor disagree	7.6% (123)
Somewhat disagree	27.5% (443)
Strongly disagree	40.0% (644)

Individuals feel confident using the transportation opportunities provided by the setting.

	Percent (<i>n</i>)
Strongly agree	81.9% (1320)
Somewhat agree	11.2% (181)
Neither agree nor disagree	6.0% (96)
Somewhat disagree	0.6% (10)
Strongly disagree	0.3% (5)

A transportation schedule is posted in a common area at the setting.

	Percent (<i>n</i>)
Strongly agree	6.5% (104)
Somewhat agree	5.5% (88)
Neither agree nor disagree	22.2% (355)
Somewhat disagree	5.9% (94)
Strongly disagree	59.9% (956)

The next set of questions deals with individual choice when it comes to their care and services provided. First, we are interested in how often individuals are asked about their needs and preferences.

Thinking about the average individual at your setting, were they asked about their goals and aspirations in the past 12 months?

	Percent (<i>n</i>)
Yes	98.0% (1580)
No	0.6% (10)
Don't know	1.4% (22)

How often, if at all, do individuals make changes to their plan of care?

	Percent (<i>n</i>)
Never	1.1% (17)
Annually	7.5% (118)
Semi-annually	10.9% (171)
Monthly	1.0% (15)
As needed/ requested	79.5% (1244)

Please select whether the following occur all of the time, most of the time, some of the time, or never.

Individual complaints are addressed in a timely manner.

	Percent (<i>n</i>)
All of the time	62.7% (1021)
Most of the time	37.1% (604)
Some of the time	0.1% (1)
Never	0.1% (2)

Individuals make changes to their plan of care as needed.

	Percent (<i>n</i>)
All of the time	55.5% (900)
Most of the time	33.5% (543)
Some of the time	9.1% (147)
Never	2.0% (33)

Individuals with concerns, discuss the concerns with the setting staff.

	Percent (<i>n</i>)
All of the time	70.0% (1141)
Most of the time	27.0% (440)
Some of the time	2.0% (33)
Never	0.9% (15)

Individuals provide input into their daily schedules.

	Percent (<i>n</i>)
All of the time	55.7% (904)
Most of the time	36.6% (593)
Some of the time	7.2% (117)
Never	0.5% (8)

Staff members do NOT discuss individuals with other staff members in public spaces.

	Percent (<i>n</i>)
All of the time	58.0% (942)
Most of the time	31.2% (507)
Some of the time	3.8% (62)
Never	7.0% (114)

When an individual files a complaint, it is considered confidential.

	Percent (<i>n</i>)
All of the time	92.4% (1505)
Most of the time	6.9% (113)
Some of the time	0.6% (9)
Never	0.1% (1)

When needed, individuals know how to request a new/additional service.

	Percent (<i>n</i>)
All of the time	45.9% (746)
Most of the time	40.5% (659)
Some of the time	11.6% (188)
Never	2.0% (33)

Individuals have the opportunity to express their level of satisfaction with the services they are receiving.

	Percent (<i>n</i>)
All of the time	85.0% (1379)
Most of the time	13.6% (221)
Some of the time	1.4% (22)
Never	0.0% (0)

How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Individuals do NOT feel comfortable expressing concerns regarding their care.

	Percent (<i>n</i>)
Strongly agree	0.6% (10)
Somewhat agree	1.6% (26)
Neither agree nor disagree	2.7% (44)
Somewhat disagree	15.8% (255)
Strongly disagree	79.3% (1282)

Individuals do NOT know how make changes to their plans of care.

	Percent (<i>n</i>)
Strongly agree	1.6% (26)
Somewhat agree	6.4% (103)
Neither agree nor disagree	8.1% (131)
Somewhat disagree	39.0% (629)
Strongly disagree	44.9% (724)

Information on how to file a complaint is easily accessible to individuals.

	Percent (<i>n</i>)
Strongly agree	62.6% (1013)
Somewhat agree	25.3% (409)
Neither agree nor disagree	6.1% (99)
Somewhat disagree	1.9% (31)
Strongly disagree	4.1% (67)

Individuals do NOT have a choice of which provider staff delivers care/support.

	Percent (<i>n</i>)
Strongly agree	2.6% (42)
Somewhat agree	25.7% (414)
Neither agree nor disagree	10.7% (173)
Somewhat disagree	34.1% (550)
Strongly disagree	27.0% (435)

Individual requests regarding their care are forwarded to independent/non-setting based case manager.

	Percent (<i>n</i>)
Strongly agree	36.5% (592)
Somewhat agree	31.9% (517)
Neither agree nor disagree	12.4% (201)
Somewhat disagree	2.3% (38)
Strongly disagree	16.8% (273)

Individual schedules for PT, OT, medication, diet, or other care options are posted in common areas (i.e., hallways).

	Percent (<i>n</i>)
Strongly agree	2.4% (39)
Somewhat agree	5.3% (85)
Neither agree nor disagree	12.4% (200)
Somewhat disagree	6.2% (100)
Strongly disagree	73.7% (1191)

Once an individual has made the choice of your setting, please select the one statement that best describes the level of individual choice at the setting.

	Percent (<i>n</i>)
Individuals have complete control over the type of care or assistance they receive or from whom they receive care or assistance from.	8.6% (140)
While individuals have a lot of choice in the type of care or assistance they receive or from whom, they are not in complete control.	87.5% (1417)
Individuals have little choice in the type of care or assistance they receive and not have control over from whom they receive care or assistance.	3.8% (62)

Please select whether the following occur all of the time, most of the time, some of the time, or never.

Individuals choose their daily clothing.

	Percent (<i>n</i>)
All of the time	68.5% (1112)
Most of the time	27.3% (443)
Some of the time	4.1% (67)
Never	0.1% (1)

Setting providers maintain control over the individual's finances.

	Percent (<i>n</i>)
All of the time	12.6% (201)
Most of the time	30.4% (484)
Some of the time	38.0% (604)
Never	19.0% (302)

Individuals are clean and well-groomed.

	Percent (<i>n</i>)
All of the time	56.5% (915)
Most of the time	43.0% (697)
Some of the time	0.4% (7)
Never	0.1% (1)

Staff members assist the individuals who need help getting dressed, at a time designated by the individual.

	Percent (<i>n</i>)
All of the time	56.9% (921)
Most of the time	36.3% (587)
Some of the time	5.3% (86)
Never	1.5% (25)

Staff members have difficulty getting along with individuals at the setting.

	Percent (<i>n</i>)
All of the time	0.7% (11)
Most of the time	0.4% (6)
Some of the time	46.1% (747)
Never	52.9% (1622)

How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Individuals are able to have their own sense of style (haircut, clothing options).

	Percent (<i>n</i>)
Strongly agree	91.6% (1488)
Somewhat agree	7.4% (120)
Neither agree nor disagree	0.8% (13)
Somewhat disagree	0.2% (3)
Strongly disagree	

Individuals are allowed to have their own checking and/or savings account.

	Percent (<i>n</i>)
Strongly agree	70.5% (1143)
Somewhat agree	16.0% (260)
Neither agree nor disagree	5.3% (86)
Somewhat disagree	2.4% (39)
Strongly disagree	5.8% (94)

Individuals are NOT allowed to own cell phones, computers, and other mobile technological devices.

	Percent (<i>n</i>)
Strongly agree	1.4% (23)
Somewhat agree	2.5% (40)
Neither agree nor disagree	1.7% (27)
Somewhat disagree	6.7% (108)
Strongly disagree	87.8% (1426)

Individuals have access to a kitchen setting.

	Percent (<i>n</i>)
Strongly agree	92.7% (1509)
Somewhat agree	5.4% (88)
Neither agree nor disagree	0.9% (14)
Somewhat disagree	0.4% (7)
Strongly disagree	0.6% (10)

Individuals do NOT have access to do their own laundry.

	Percent (<i>n</i>)
Strongly agree	1.2% (19)
Somewhat agree	1.9% (30)
Neither agree nor disagree	0.7% (12)
Somewhat disagree	3.9% (64)
Strongly disagree	92.3% (1496)

Individuals have access to a television in common areas.

	Percent (<i>n</i>)
Strongly agree	98.6% (1592)
Somewhat agree	0.7% (12)
Neither agree nor disagree	0.2% (3)
Somewhat disagree	0.0% (0)
Strongly disagree	0.5% (8)

Individuals have access to cell phones, computers, and other mobile technological devices in common areas.

	Percent (<i>n</i>)
Strongly agree	61.4% (998)
Somewhat agree	18.1% (294)
Neither agree nor disagree	13.7% (222)
Somewhat disagree	3.8% (62)
Strongly disagree	3.0% (49)

Appendix C**Assessment of Illinois Home and Community Based Services
Agencies Providing Non-Residential Services**

Developed to assist the Illinois Statewide Transition Plan

Conducted by the Survey Research Office, Center for State Policy & Leadership, University
of Illinois Springfield

Draft report issued on January 22, 2015

Introduction

The purpose of this study is to examine the policies, procedures, and activities of non-residential settings for Home or Community Based Service waivers. In order to accomplish this, the UIS Survey Research Office, Center for State Policy & Leadership, used a multi-mode methodology in order to allow agencies and settings to self-report on the types of policies and procedures in place throughout settings in Illinois. This report contains four chapters in addition to this introduction.

1. **Scope of Project-** This section provides a brief introduction to the Centers for Medicare and Medicaid Services' (CMS) final rule relating to Home and Community Based Services (HCBS) for Medicaid-funded long term services and supports provided in residential and non-residential home and community-based settings.
2. **Summary of Results-** The purpose of this section is to summarize the results of the two surveys as well as provide an overview of the “Level of Autonomy Score” and the “Frequency of Independent Behaviors Score.” These scores are the numerical values that will be used to identify the key areas of the Illinois Statewide Transition Plan. This section contains four subsections:
 - a. Results from the Agency-Specific Surveys
 - b. Characteristics of the Non-Residential Settings
 - c. Individuals' Access to the Community in Non-Residential Settings
 - d. Individuals' Personal Choice in Care Options in Non-Residential Settings.

This section also provides direction for the next steps in this process.

3. **Methodology-** This section provides a detailed analysis of the methodological design of this project. There were systematic decisions on how to assess all aspects of the settings from engagement with the community, transportation opportunities, dining and meal accommodations, and personal autonomy and choice in care options. A detailed discussion of these decisions and the methodology employed by UIS researchers is provided in the methodology section.
4. **Survey Report-** This is a topline report which includes complete question wording and the frequency of responses to each of the answer categories.

Scope of Project

The Centers for Medicare and Medicaid Services (CMS) published its final rule relating to Home and Community Based Services (HCBS) for Medicaid-funded long term services and supports provided in residential and non-residential home and community-based settings. The final rule took effect on March 17, 2014. According to this rule, states are required to submit transition plans to CMS within one year of the effective date indicating how they intend to comply with the new requirements within a reasonable time period.

In an effort to follow the CMS final rule guidance, the Illinois Department of Healthcare and Family Services, along with the Department of Human Services and the Department on Aging, developed several surveys with assistance of researchers from the UIS Survey Research Office in order to assess the State's current compliance with the new regulations specific to the residential and non-residential settings requirements. This report deals specifically with non-residential settings offered through HCBS waivers.

The following Illinois HCBS waivers are included in this analysis:

- Children and Young Adults with Developmental Disabilities
- Children that are Technology Dependent/Medically Fragile
- Persons with Disabilities
- Persons with Brain Injuries (BI)
- Adults with Developmental Disabilities
- Persons who are Elderly
- Persons with HIV or AIDs
- Supportive Living Facilities

The following types of settings are **not** included in this classification:

- Hospitals
- Institutions for mental diseases
- An *intermediate* care facility for individuals with intellectual disabilities
- Nursing facilities
- Mental health or DASA residential sites
- Residences for private pay residents only
- Individuals receiving care in their private residences/family homes

This report provides the results of the examination of non-residential settings for Illinois HCBS waivers.

Summary of Results

The results chapter contains four main sections: Results from the Agency-Specific Surveys, Characteristics of the Non-Residential Settings, Individuals' Access to the Community in Non-Residential Settings, and Individuals' Personal Choice in Care Options in Non-Residential Settings. This executive summary provides an overview of each of the sections as well as a synopsis of the findings. It also provides an overview of the “Level of Autonomy Score” and a “Frequency of Independent Behaviors Score.” These scores are the numerical values that will be used to identify the next steps as part of the Illinois Statewide Transition Plan. This section also provides direction for the next steps in this process.

Results from the Agency-Specific Surveys

The main survey required from each agency which operates at least one non-residential setting in Illinois was titled the “Agency-specific survey.” Agencies were able to complete this survey online, paper copies sent via U.S. mail, or over the phone with trained SRO interviewers. Of the 218 agencies operating at least one non-residential setting for Illinois waiver HCBS participants, 205 completed the agency-specific form. This resulted in a 95 percent completion rate among all agencies. The agencies that did not complete the agency-specific form will be contacted by their corresponding state agency in early 2015 in order to assess whether or not these agencies operate non-residential settings in Illinois. Those that do will be required to complete the agency-specific survey with an individual from the corresponding state agency (Illinois Departments of Healthcare and Family Services, Human Services, or Aging).

There are two main purposes of the agency-specific survey:

- 1) Determine the number of non-residential settings in Illinois for HCBS waivers;
- 2) Identify the agencies that have agency-wide policies and procedures that regulate various aspects of the daily operations of their settings.

The main findings of the agency-specific survey are listed below:

- There are currently 459 non-residential settings in Illinois.
- The majority of agencies have agency-wide policies that apply to the setting(s) regarding three issues: (a) visitation procedures, (b) right to privacy, and (c) community integration.
- The majority of agencies do not have agency-wide policies that limit the setting(s) for the following: (a) staff-individual interaction, (b) community engagement, and (c) engaging in legal activities. For the frequency of responses to these questions, please see the topline report at the end of this report.
- Eighty percent of settings have policies to support access to the greater community.
- Ninety percent of settings have policies that facilitate individual choices in care and services.
- Ninety-four percent of settings have policies that ensure individual privacy.
- Ninety-five percent of settings are physically accessible to the majority of individuals.

Characteristics of the Non-Residential Settings

The setting-specific survey completed by 409 non-residential settings allows researchers to gain unique insight into the demographic characteristics of the non-residential settings. The demographic section provides three important pieces of information.

- 1) The number of individuals (both Illinois HCBS waivers and others) at each non-residential setting.
- 2) The physical location and type of building of each setting.
- 3) The controlling entity for each of the settings.

Number of individuals

The mean number of waiver participants supported at each setting is 79.32, with the largest setting supporting 2744 individuals. This is out of an average number of 163 total individuals (waiver and non-waiver participants) at the non-residential settings.

Physical location and type of building

- Six settings (1.5%) report that they are “physically connected to a hospital, nursing facility, institution for mental disease, or an intermediate care facility for individuals with intellectual disabilities.”
- Twenty-eight (6.9%) report that while they are not physically connected, they are on the grounds or adjacent to these types of facilities.
- The majority (91.6%) report that they are not physically connect nor adjacent to these type of facilities.

When we examine types of settings, we find that the majority of respondents are Developmental Training settings with 68.7 percent reporting that this describes their setting.

Table 1. Types of settings

	Percent (<i>n</i>)
Adult Day Care	16.9% (69)
Adult Day Health Services	3.9% (16)
Developmental Training	68.7% (281)
Prevocational Services (services provided under the brain injury waiver)	0.2% (1)
Supported Employment	5.1% (21)

When asked to describe this setting as located in a rural area (located outside of a metropolitan area), located in a suburban area, or located in an urban area, respondents were split evenly across all three categories. As seen in the table below, a slightly higher percentage reported being in a rural areas, 37.8 percent compared to 34.3 percent who reported being in a suburban area, and 34.3 percent who reported being in an urban area.

Table 2. Description of settings

	Percent (<i>n</i>)
Located in a rural area (located outside of a metropolitan area)	37.8% (153)
Located in a suburban area	34.3% (139)
Located in an urban area	27.9% (113)

When asked to describe the setting, the majority described it as a stand-alone building located on a public street or highway. Table 3 provides the complete list.

Table 3. Physical description of settings

	Percent (<i>n</i>)
Multiple settings co-located/campus	14.2% (58)
A gated/secured community	1.2% (5)
Stand-alone building located on a public street or highway	84.6% (346)
Hospital	0.5% (2)
Nursing homes	0.7% (3)

Controlling Entity

In addition, when asked what entity or entities control(s) the policies or procedures for the setting, 84 percent report that it is the parent agency or organization. Eleven percent report that the individual setting controls the policies or procedures (46), followed by a subsidiary or foundation (0.2%).

Finally, settings were told to identify all of the state agencies from which they receive funding for their services. As seen in the table below, the Illinois Department of Human Services is the largest funder for services.

Table 4. State Agency Funding Services

	Percent (<i>n</i>)
Illinois Department of Healthcare and Family Services	28.1% (115)
Illinois Department of Human Services Division of Developmental Disabilities	81.9% (335)
Illinois Department of Human Services Division of Rehabilitation Services	37.2% (77)
Illinois Department on Aging	18.8% (152)

The final two results sections discuss the results of the setting-specific survey. The setting-specific survey deals with all aspects of the non-residential settings. In order to reduce the complexity of this instrument, we have categorized these into two factors: Individual's Access to the Community in Non-Residential Settings and Individuals' Personal Autonomy and Choice in Care Options in Non-Residential Settings. Each of these sections has the following subsections.

Individuals' Access to the Community in Non-Residential Settings

- Community Engagement
- Transportation Opportunities

Individuals' Personal Choice in Care Options in Non-Residential Settings

- Individual Care Plans
- Setting Accommodations

Each of settings receives two scores within each of the four subsections: a “Level of Autonomy Score” and a “Frequency of Independent Behaviors Score.” These scores measure related but unique concepts. The “Level of Autonomy Score” measures what level of autonomy or personal freedom individuals experience based on the policies of each non-residential setting. The “Frequency of Independent Behaviors Score” measures how often individuals engage in these autonomous behaviors. These scores are calculated similarly among all of the four subsections.

“Level of Autonomy Score”- This score is calculated using items on a five-point Likert scale ranging from “Strongly Agree (5), Somewhat Agree (4), Neither Agree nor Disagree (3), Somewhat Disagree (2), Strongly Agree (1).” Settings were asked to report their level of agreement on a variety of different items measuring each of the four subsections. For example, one of the items measuring community engagement using the Likert scale asked respondents their level of agreement with the following statement: *Individuals are given easy access to the community outside of the setting.* While each of the subsections may have a different number of items measuring the concept, the “Level of Autonomy Scores” are standardized.

The scores for each of the subsections range from 1 to 5, where 1 indicates the lowest level of autonomy and 5 indicates the highest level of autonomy. The table below provides the mean “Level of Autonomy Score” for each of the subsections with the standard deviations in parentheses.

Table 5. Level of Autonomy Scores

	Level of Autonomy Score
Community Engagement	3.76 (.64)
Transportation Opportunities	3.84 (.67)
Individual Care Plans	3.78 (.59)
Setting Accommodations	3.79 (.40)

As seen in the table above, all of the “Level of Autonomy Scores” range between the neutral category (3: Neither Agree nor Disagree”) and the strong agreement category (5: “Strongly Agree”). Overall, this indicates a high level of autonomy in each of the four subsections. Transportation Opportunities has the highest “Level of Autonomy Score” while Community Engagement has the lowest “Level of Autonomy Score.” To find a detailed discussion of the items that constructed each of these scores, please see the corresponding section in the following pages.

“Frequency of Independent Behaviors Score”- This score is calculated using a four-point frequency measure ranging from “All of the time” (4), “Most of the time” (3), “Some of the time” (2), “Never” (1). Settings were asked to report how often a variety of different behaviors occurs for each of the four subsections. For example, one of the items measuring individual care plans using the frequency scale asks respondents to report the frequency of the following item: *Individuals' complaints are addressed in a timely manner.*

The scores for each of the subsections range from 1 to 4, where 1 indicates the lowest frequency amount and 4 indicates the highest frequency amount. The table below provides the mean “Frequency of Independent Behaviors Score” for each of the subsections with the standard deviations in parentheses.

Table 6. Frequency of Independent Behaviors Score

	Frequency of Independent Behaviors Score
Community Engagement	2.85 (.69)
Transportation Opportunities	3.47 (.56)
Individual Care Plans	3.31 (.31)
Setting Accommodations	3.07 (.73)

As seen in the table above, all of the “Frequency of Independent Behaviors Scores” range between “Some of the Time” (2) and “All of the Time” (4). Individual Care Plans has the highest “Frequency of Independent Behaviors Score” at 3.31. This indicates that when it comes to individuals’ care plans, the majority of individuals are able to assert a high level of independent behavior. The lowest “Frequency of Independent Behaviors Score” is Community Engagement with 2.85. To find a detailed discussion of the items that constructed each of these scores, please see the corresponding section in the following pages.

The following pages discuss the four subsections of the results section. Each of the sections provides an overview of the findings (bullet points), and detailed descriptions of both the “Level of Autonomy Score” and the “Frequency of Independent Behaviors Score.”

Individuals’ Access to the Community in Non-Residential Settings

This results section is concerned with the policies and procedures in place that allow individuals to be able to access the external community, outside of the non-residential setting. This section contains two subsections: Community Engagement and Transportation Opportunities.

Community Engagement

- Overall, community engagement within the nonresidential settings scored the lowest on both the measure of Level of Autonomy as well as the Frequency of Independent Behaviors.
- Slightly more than half of non-residential settings report that individuals regularly engage in community activities while at the setting (55.3 percent), compared to 35.5 percent who report that individuals engage occasionally, and 9.2 percent who report that the individuals do not participate often.
- Sixty-percent of non-residential settings report that helping individuals obtain integrated employment opportunities is part of their service.
- The overall “Level of Autonomy Score” for community engagement is 3.76 (out of 5); The “Frequency of Independent Behaviors Score” for community engagement is 2.85 (out of 4).

The overall “Level of Autonomy Score” for community engagement is 3.76, which indicates a lower level of autonomy for participants in terms of their engagement in the community. When we examine the six items that constructed this score, we find slight differences among the different measures. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates a low level of autonomy). The item that had the highest percent of respondents reporting that a low autonomy score is “Participants are able to come and go as they please.” One-fourth of settings reported that this was not true at their setting.

Table 7. Items of “Level of Autonomy Score”

	Percent reporting lowest rating of autonomy
Participants are able to come and go as they please.	25.1%
Participants know where to find information on community activities.	3.3%
Participants are given easy access to the community outside of the setting.	4.8%

The “Frequency of Independent Behaviors Score” was constructed using six items listed in the table below. The overall score for community engagement is 2.85, which indicates the lowest level of the frequency of independent behaviors. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the survey response of “never,” the lowest frequency score). As you can see in the table, the item that had the highest percent of respondents reporting a low frequency score is “participants and community members interact at the setting.” However, fewer than 10 percent reported a “never” for all of these items.

Table 8. Items of “Frequency of Independent Behaviors Score”

	Percent reporting lowest level of frequency
Participants and community members interact at the setting.	5.8%
Participants pursue integrated/competitive employment opportunities.	5.6%
Participants pursue other employment opportunities (both paid and volunteer).	4.8%
Participants have the opportunity to engage in community activities while at the setting (both at the setting and in the community).	3.0%
Individuals pursue competitive employment opportunities.	3.0%
Interested participants are given the resources on how to obtain employment.	2.8%
Participants talk about community activities occurring outside of the setting.	1.5%

Transportation Opportunities

- Overall, transportation opportunities (both in terms of level of autonomy and frequency of independent behaviors) received the highest evaluation by non-residential settings.
- Eighty-three percent of non-residential settings report that there are retail businesses near their setting.
- Ninety percent of non-residential settings provide regularly-scheduled transportation opportunities to participants.
- The overall “Level of Autonomy Score” for transportation opportunities is 3.84; the “Frequency of Independent Behaviors Score” for transportation opportunities is 3.47.

The overall “Level of Autonomy Score” for transportation opportunities is 3.84, which indicates a high level of autonomy for participants in terms of their transportation opportunities. When we examine the four items that constructed this score, we find slight differences among the items. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates a low level of autonomy). As you see in the table, the item that had the highest percent of respondents reporting a low autonomy score is “transportation opportunities are not limited for participants.”

Table 9. Items of “Level of Autonomy Score”

	Percent reporting lowest rating of autonomy
There are public transportation opportunities available to participants in the setting.	8.9%
The setting provides transportation opportunities to participants outside of regularly scheduled options.	12.7%
Transportation opportunities are not limited for participants.	15.9%
Participants feel confident using the transportation opportunities provided by the setting.	1.1%

The “Frequency of Independent Behaviors Score” was constructed using three items listed in the table below. The overall score for transportation opportunities is 3.475, which indicates a high level of the frequency of independent behaviors in terms of transportation opportunities. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the survey response of “never,” the lowest frequency score). As you can see in the table, the item that had the highest percent of respondents reporting a low frequency score is “participants are informed/educated on how to use public transportation.” Yet, less than 3 percent of non-residential settings reported that this “never” happens.

Table 10. Items of “Frequency of Independent Behaviors Score”

	Percent reporting lowest level of frequency
Participants are informed/educated on how to use public transportation.	2.5%
Participants use the transportation opportunities provided by the setting.	0.3%
Participants know how to contact a staff member about transportation opportunities.	1.6%

Participants’ Personal Choice in Care Options in Non-Residential Settings

This results section is concerned about the level of personal choice individual participants have while attending the settings. This includes their individual care plans, their sense of individuality, their dining arrangements, and their interactions with visitors and staff members. This section contains two subsections: Individual Care Plans and Setting Accommodations.

Individual Care Plans

- A vital component of the new federal regulations is that participants at non-residential settings have flexibility and freedom in developing their individual care plans. The results of this survey indicate that the frequency of independent behaviors associated with individual care plans is at a moderate level.
- The majority of the non-residential settings that responded to this survey report that participants have a lot of choice.
- Almost all of the settings (97%) report that the average individual at their setting has been asked about their goals and aspirations in the past 12 months and 69.7 percent report that participants make changes to their plan of care “as needed or as requested.”
- The overall “Level of Autonomy Score” for individual care plans is 3.78, the “Frequency of Independent Behaviors Score” for individual care plans is 3.31.

The overall “Level of Autonomy Score” for individual care plans is 3.78, which indicates a moderate level of autonomy for participants in terms of their individual care plans. When we examine the six items that constructed this score, we find slight differences among the measures. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the lowest level of autonomy). The item that had the highest percent of respondents reporting the lowest autonomy score is “Participants’ requests regarding their care are forward to an independent/non-setting based case manager.”

Table 11. Items of “Level of Autonomy Score”

	Percent reporting lowest rating of autonomy
Participants feel comfortable expressing concerns regarding their care.	1.0%
Participants know how make changes to their plans of care.	0.8%
Information on how to file a complaint is easily accessible to participants.	5.5%
Participants have a choice of which provider staff delivers care/support.	4.5
Participants’ requests regarding their care are forwarded to an independent/non-setting based case manager.	13.9%
Schedules for PT, OT, medication, diet, or other care options are NOT posted in common areas (i.e., hallways).	7.3%

The “Frequency of Independent Behaviors Score” was constructed using eight items listed in the table below. The overall score for individual care plan is 3.31, which indicates the high level of the frequency of independent behaviors in terms of individual care planning. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the survey response of “never,” the lowest frequency score). The item that had the highest percent of respondents reporting a low frequency score is “Staff members do not discuss participants with other staff members in public spaces.” 7 percent of settings reporting that this never happens.

Table 12. Items of “Frequency of Independent Behaviors Score”

	Percent reporting lowest level of frequency
Individual complaints are addressed in a timely manner.	0.0%
Participants make changes to their plan of care as needed.	2.6%
Participants with concerns, discuss the concerns with the setting staff.	0.8%
Participants provide input into their daily schedules.	1.0%
Staff members do not discuss participants with other staff members in public spaces.	7.1%
When an individual files a complaint, it is considered confidential.	0.3%
When needed, participants know how to request a new/additional service.	1.3%
Participants have the opportunity to express their level of satisfaction with the services they are receiving.	0.0%

Setting Accommodations

- One way that participants are able to express their own personal choice is in their dining and meal decisions. According to the survey results, only 35.6 percent of non-residential settings provide or arrange for meals and food for participants while at the setting. Of those, only one-fourth report that the individuals have a lot of choice when it comes to dining/food options.
- According to the survey results, participants have a moderate level of autonomy when it comes to their setting accommodations as well as demonstrate a moderate amount of independent behaviors.
- The overall “Level of Autonomy Score” for setting accommodations is 3.80; the “Frequency of Independent Behaviors Score” is 3.07.

The overall “Level of Autonomy Score” for setting accommodations is 3.80. When we examine the ten items that constructed this score, we find slight differences among the items. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the lowest level of autonomy). The item that had the highest percent of respondents reporting the lowest autonomy score is “Participants are able to set their own dining/meal-time schedules.”

Table 13. Items of “Level of Autonomy Score”

	Percent
Persons without disabilities (other than staff members) engage with the participants at the setting.	6.2%
Community members are allowed to visit the setting at any time.	2.0%
Participants at the setting use a common entrance.	7.7%
The setting is not located in the same physical structure where individuals live or are treated on a permanent or temporary basis.	4.4%
Participants are free to move about public areas within the setting.	1.2%
Community members come to the setting to discuss external community activities.	11.2%
Participants have the opportunity to access areas that provide privacy while at the setting (excluding restroom facilities).	2.2%
Participants are not assigned seating during meal-times.	3.4%
Participants are able to set their own dining/meal-time schedules.	32.8%
Participants engage with others during meal-times.	1.6%

The “Frequency of Independent Behaviors Score” was constructed using two items listed in the table below. It is important to note that this only applies to the 143 non-residential settings that provide food or meal accommodations. The overall score is 3.07, which indicates a moderate level of the frequency of independent behaviors in terms for setting accommodations. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the survey response of “never,” the lowest frequency score).

Table 14. Items of “Frequency of Independent Behaviors Score”

	Percent reporting lowest level of frequency
There is more than one meal option during meal-times.	11.9%
Between designated meal-times, the setting provides other food or refreshments.	6.3%

The Next Steps in the Illinois Statewide Transition Plan

One of the main purposes of these surveys is to help the Illinois Department of Healthcare and Family Services, the Department of Human Services, and the Department on Aging develop the statewide transition plan as dictated by the Centers for Medicare and Medicaid Services (CMS) final rule relating to Home and Community Based Services (HCBS) for Medicaid-funded long term services and supports. The UIS Survey Research Office suggests the following steps in order to follow these federal guidelines.

1. Of the 218 agencies operating at least one non-residential setting for Illinois waiver HCBS participants, 205 completed the agency-specific form. The agencies that did not complete the agency-specific form should be contacted by their corresponding state agency in early 2015 in order to assess whether or not these agencies operate non-residential settings in Illinois. Those that do will be required to complete the agency-specific survey with an individual from the corresponding state agency (Illinois Departments of Healthcare and Family Services, Human Services, or Aging).
2. Representatives designated by the Illinois Department of Healthcare and Family Services, the Department of Human Services, and the Department on Aging should conduct site visits at all of the 6 settings that reported that they were physically connected to a hospital, nursing facility, institution for mental diseases, or an intermediate care facility for participants with intellectual disabilities.
3. Representatives designated by the Illinois Departments of Healthcare and Family Services, Human Services, and Aging should conduct site visits of the non-residential settings that scored the lowest on either the “Level of Autonomy” and “Frequency of Independent Behavior” scores. In order to be able to compare the different scores (which were computed using a different number of items), the scores were standardized with the mean score for each of the items being a “0,” and the standard deviation being +/- 1. Therefore, we suggest that site visits are conducted at each setting that scored significantly lower than median score on each of the different scores as well as those settings that score significantly lower than 99 percent of the sample on any of the individual score.
4. Representatives designated by the Illinois Departments of Healthcare and Family Services, Human Services, and Aging should conduct site visits of a sample of the non-residential settings who scored within the mean on the “Level of Autonomy” and within the mean “Frequency of Independent Behavior” scores. Even though steps were taken to lower the likelihood of response bias, it is still possible that bias affected how some agencies responded. People may be inclined, for example, to give the response that they think will make them look good, rather than the one that accurately represents their situation. Consequently, we suggest that site visits be made to no more than 2 percent of the sample as a way to validate the survey results.

Methodology

The HCBS non-residential survey is actually two surveys: an agency-specific survey and a setting-specific survey. Every agency was required to fill out both an agency-specific non-residential survey as well as a setting-specific non-residential survey for each of their non-residential settings. Settings were able to participate in the surveys via online, mail, and phone.

The Illinois Department of Healthcare and Family Services, along with the Department of Human Services and the Department on Aging provided a list of agencies which operate non-residential settings offered through HCBS waivers. A total of 218 agencies met these guidelines. Mailing addresses, contact information for the director of each agency, and email addresses were provided by each of the corresponding state agencies. All agencies were contacted at least five times by researchers at the Survey Research Office (SRO).

The first contact to the agencies was through emails from their corresponding state agencies: Illinois Departments of Healthcare and Family Services, Human Services, or Aging. After the email distribution, the same information was sent from the SRO in an introductory letter via U.S. Postal Service on October 17, 2014. This correspondence discussed the need for Illinois to take inventory of all supportive congregate and/or group non-residential settings that are not hospitals, nursing homes, IMDs or ICF-DDs. This letter also informed the agency that they will be receiving information on how to complete a survey for their non-residential settings from the University of Illinois at Springfield (UIS). In addition, the recipients received specific language explaining that while there are no right or wrong answers to questions, their participation in the survey is mandatory.

The first round of survey instruments was sent to each of the 218 agencies via U.S. Postal Service on October 31st, 2014. Included in the mailing was an introductory letter to the director of the agency, a agency-specific survey, six copies of the setting-specific survey, and five business reply envelopes. The agency-specific survey contained an identifying tracking number in order for SRO researchers to keep track of the agencies who had completed the surveys. Settings were instructed that they could complete the hard copies of the surveys included in the mailing packet or complete the surveys online through provided URLs. If agencies needed additional copies of the setting-specific survey, they were instructed to contact the SRO via email or telephone.

A reminder postcard was sent to all of the agencies on November 13th, 2014. This postcard contained the project identification number for each of the agencies as well the URL to complete the surveys online. A second mailing occurred on November 21st, 2014. This mailing included the introductory letter, the agency-specific survey, and one copy of the setting-specific survey. Agencies that had not completed the surveys by January 5th, 2015 received phone calls from trained SRO interviewers. These phone calls were placed at different dates and times of the work week in an effort to increase the number of responses. Phone interviews concluded on January 16, 2015. The survey closed on January 20, 2015.

Through these various methods, SRO was able to get information through the survey from 205 of the 218 agencies (93.6%) that operate non-residential settings in Illinois. In addition, these agencies are responsible for operating 409 non-residential settings in Illinois.

Response bias may occur within surveys that rely on self-assessment, especially in situations in which funding may be in jeopardy. The following steps were taken to mitigate this bias:

1) The instructions attached to both surveys -- agency-specific and setting-specific -- emphasized that the data provided by both the agency and the setting are for informational purposes only and will not be used to assess the federal compliance of either the agency or the setting.

2) The following information was included on every page of the setting-specific survey:

REMINDER: The input you provide will be used to inform the Transition Plan and will NOT be used to evaluate whether the setting is currently in compliance with the new federal requirements. For example, selecting “Never” or “Strongly Disagree” for one of the items does not indicate that you are not in compliance. *Please answer the questions based on what “typically occurs” in the setting.* The emphasis is on what are in the setting’s policies and procedures. It is recognized that individual’s plans of care may dictate certain restrictions that would be documented to cause harm or reflect one’s abilities.

3) The majority of both surveys used Likert scales to effectively evaluate agencies and settings. The Likert technique is one of the most used and most validated survey designs. It involves asking a respondent to indicate how much he/she agrees or disagrees with each of a set of statements. The surveys used a five-point Likert response scale: strongly disagree, disagree, neutral, agree, strongly agree.

4) Each survey included both positive statements (Participants have access to a kitchen setting.) and negative statements. (Participants do NOT have access to do their own laundry.) When a survey or section of a survey contains only positive or only negative items, research shows that this can influence how people respond. A set of items worded only positively (with no negative items mixed in) can induce a positive bias from respondents. They respond by agreeing with those items more than they might if the set also included negatively worded items. The same goes for only framing survey items negatively. Thus, to reduce this bias, the surveys always include a mix of positively and negatively worded items.

5) In addition to the Likert design, the survey included questions on the frequency of certain behaviors, rather than just asking whether the behavior occurs or not. The questions included asking respondents “how often” certain activities occur at the setting. The four-point response categories ranged from “all of the time,” “most of the time,” “some of the time,” and “never.” Including this scale allows participants to provide more specific and useful information.

The following report is separated into four sections: Results from the Agency-specific Surveys, Demographics of the Non-Residential Settings, Participants’ Access to the Community in Non-Residential Settings, Participants’ Personal Autonomy and Choice in Care Options in Non-Residential Settings.

If you have any questions or comments about this report, please contact the Survey Research Office:

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Topline Report

Agency-Specific Surveys

How much, if at all, do you agree with the following statements about your agency? Do you strongly agree, somewhat agree, somewhat disagree, or strongly disagree? If you do not know the answer, please check “Don’t know.”

There are agency-wide policies that apply to the setting(s) regarding visitation from community members, this refers to participants who are not currently being treated by the setting.

	Percent (<i>n</i>)
Strongly agree	49.0% (96)
Somewhat agree	29.6% (58)
Somewhat disagree	7.7% (15)
Strongly disagree	9.7% (19)
Don’t know	4.1% (8)

There are agency-wide policies and procedures that disallow participants from engaging in legal activities at its setting(s).

	Percent (<i>n</i>)
Strongly agree	11.2% (22)
Somewhat agree	7.7% (15)
Somewhat disagree	11.7% (23)
Strongly disagree	51.0% (100)
Don’t know	18.4% (36)

There are agency-wide policies and procedures that disallow participants from engaging in community activities at its setting(s).

	Percent (<i>n</i>)
Strongly agree	3.1% (6)
Somewhat agree	3.6% (7)
Somewhat disagree	8.7% (17)
Strongly disagree	79.1% (155)
Don’t know	5.6% (11)

There are agency-wide policies and procedures that limit individual interaction with staff members at the setting(s).

	Percent (<i>n</i>)
Strongly agree	4.1% (8)
Somewhat agree	7.2% (14)
Somewhat disagree	7.7% (15)
Strongly disagree	80.0% (156)
Don’t know	1.0% (2)

There are agency-wide policies and procedures that ensure an individual's right to privacy.

	Percent (<i>n</i>)
Strongly agree	97.5% (193)
Somewhat agree	2.0% (4)
Somewhat disagree	0% (0)
Strongly disagree	0.5% (1)
Don't know	0% (0)

There are agency-wide policies and procedures that ensure that the setting(s) are integrated in the community.

	Percent (<i>n</i>)
Strongly agree	59.7% (117)
Somewhat agree	33.7% (66)
Somewhat disagree	2.6% (5)
Strongly disagree	1.5% (3)
Don't know	2.6% (5)

Please answer whether the following apply to all of your settings, some of your settings, none of your settings. If you do not know the answer, please check "Don't know."

There are policies to support access to the greater community at the setting(s).

	Percent (<i>n</i>)
Applies to all of our settings	79.7% (157)
Applies to some of our settings	11.2% (22)
Applies to none of our settings	4.1% (8)
Don't know	5.1% (10)

There are policies that facilitate individual choice in types of services provided to the individual at the setting.

	Percent (<i>n</i>)
Applies to all of our settings	90.9% (180)
Applies to some of our settings	5.6% (11)
Applies to none of our settings	3.5% (7)
Don't know	0% (0)

The setting is physically accessible to the majority of participants.

	Percent (<i>n</i>)
Applies to all of our settings	94.4% (187)
Applies to some of our settings	5.6% (11)
Applies to none of our settings	0% (0)
Don't know	0% (0)

There are policies that ensure participants have privacy while at the setting(s).

	Percent (<i>n</i>)
Applies to all of our settings	93.9% (186)
Applies to some of our settings	3.5% (7)
Applies to none of our settings	1.5% (3)
Don't know	1.0% (2)

Setting-Specific Survey

How many HCBS or other State-funded approved participants are supported at this location?

	Percent (<i>n</i>)
Less than five	9.5% (37)
Five to 10 participants	4.6% (18)
11-20 participants	12.6% (53)
21-50 participants	27.6% (116)
More than 50 participants	45.7% (185)

Out of how many total participants?

	Percent (<i>n</i>)
Less than five	1.3% (5)
Five to 10 participants	4.3% (11)
11-20 participants	8.3% (20)
21-50 participants	33.1% (88)
More than 50 participants	53.0% (285)

Which of the following best describes your setting?

	Percent (<i>n</i>)
Physically connected to a hospital, nursing facility, institution for mental diseases, or an intermediate care facility for participants with intellectual disabilities.	1.5% (6)
Not physically connected but on the grounds or adjacent to a hospital, nursing facility, institution for mental diseases, or an intermediate care facility for participants with intellectual disabilities.	6.9% (28)
Not physically connected or adjacent hospital, nursing facility, institution for mental diseases, or an intermediate care facility for participants with intellectual disabilities.	91.6% (373)

Please identify all state agencies with whom you may receive funding to provide services for:

	Percent (n)
Illinois Department of Healthcare and Family Services	28.1% (115)
Illinois Department of Human Services Division of Developmental Disabilities	81.9% (335)
Illinois Department of Human Services Division of Rehabilitation Services	37.2% (77)
Illinois Department on Aging	18.8% (152)

Which of the following best describes the setting?

	Percent (n)
Adult Day Care	16.9% (69)
Adult Day Health Services	3.9% (16)
Developmental Training	68.7% (281)
Prevocational Services (services provided under the brain injury waiver)	0.2% (1)
Supported Employment	5.1% (21)
Other, please specify:	5.1% (21)

Would you describe this setting as located in a rural area, located in a suburban area, or located in an urban area?

	Percent (n)
Located in a rural area (located outside of a metropolitan area)	37.8% (153)
Located in a suburban area	34.3% (139)
Located in an urban area	27.9% (113)

What entity/entities control(s) the policies or procedures for this setting?

	Percent (n)
The parent agency/organization	84.0% (341)
The individual setting	11.3% (46)
A subsidiary or foundation	0.2% (1)
Other, please specify:	4.4% (18)

Others mentioned: Board of Directors, Both parent and individual setting, Both the individual setting and the parent organization, Both the parent agency and the individual setting, Both the parent organization and the individual setting, Both the setting and the parent agency, IL Dept. of Human Services, Illinois Department of Transportation, The Board of Directors, The parent agency/organization; The individual setting, Volunteer Board of Director from member churches and Executive Director

Please select all of the following that describe this setting:

	Percent (<i>n</i>)
Multiple settings co-located/campus	14.2% (58)
A gated/secured community	1.2% (5)
Stand-alone building located on a public street or highway	84.6% (346)
Hospital	0.5% (2)
Nursing homes	0.7% (3)

Setting Characteristics

The next set of questions deal with the accommodations provided by your non-residential setting for participants. How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Persons without disabilities (other than staff members) engage with the participants at this setting.

	Percent (<i>n</i>)
Strongly agree	43.5% (175)
Somewhat agree	29.1% (117)
Neither agree nor disagree	8.2% (33)
Somewhat disagree	12.9% (52)
Strongly disagree	6.2% (25)

Community members are NOT allowed to visit the setting at any time.

	Percent (<i>n</i>)
Strongly agree	2.0% (8)
Somewhat agree	2.7% (11)
Neither agree nor disagree	4.0% (16)
Somewhat disagree	13.4% (54)
Strongly disagree	77.9% (314)

Participants at the setting use a common entrance.

	Percent (<i>n</i>)
Strongly agree	71.1% (286)
Somewhat agree	14.4% (58)
Neither agree nor disagree	3.7% (15)
Somewhat disagree	3.0% (12)
Strongly disagree	7.7% (31)

The setting is located in the same physical structure where participants live or are treated on a permanent or temporary basis.

	Percent (<i>n</i>)
Strongly agree	4.4% (18)
Somewhat agree	3.5% (14)
Neither agree nor disagree	2.0% (8)
Somewhat disagree	3.5% (14)
Strongly disagree	86.7% (351)

Participants are free to move about public areas within the setting (common areas, dining rooms).

	Percent (<i>n</i>)
Strongly agree	74.6% (302)
Somewhat agree	17.5% (71)
Neither agree nor disagree	2.5% (10)
Somewhat disagree	4.2% (17)
Strongly disagree	1.2% (5)

Participants have the opportunity to access areas that provide privacy while at the setting (excluding restroom facilities).

	Percent (<i>n</i>)
Strongly agree	68.6% (227)
Somewhat agree	17.6% (71)
Neither agree nor disagree	5.2% (21)
Somewhat disagree	6.4% (26)
Strongly disagree	2.2% (9)

Community members come to the setting to discuss external community activities.

	Percent (<i>n</i>)
Strongly agree	31.9% (128)
Somewhat agree	31.9% (128)
Neither agree nor disagree	16.0% (64)
Somewhat disagree	9.0% (36)
Strongly disagree	11.2% (45)

Once an individual has made the choice of your setting, please select the one statement that best describes the level of individual choice at the setting.

	Percent (<i>n</i>)
Participants have complete control over the type of care or assistance they receive or from whom they receive care or assistance from.	20.6% (83)
While participants have a lot of choice in the type of care or assistance they receive or from whom, they are not in complete control.	75.7% (305)
Participants have little choice in the type of care or assistance they receive and not have control over from whom they receive care or assistance.	3.7% (15)

Community Activities

The first set of questions deal with access to community activities (events occurring **external to your setting** such as religious services, shopping, employment, or other social/personal/family events outside of the setting). We are interested in how participants participate in unscheduled and scheduled community activities at your setting.

How often, if at all, do participants participate in community activities while residing at the setting? Would you say that the majority of participants participate in these activities regularly, occasionally, or not often at all?

	Percent (<i>n</i>)
Regularly	55.3% (223)
Occasionally	35.5% (143)
Not often at all	9.2% (37)

Is helping participants obtain volunteer opportunities part of your service?

	Percent (<i>n</i>)
Yes	67.0% (236)
No	33.0% (116)

Please select whether the following occur all of the time, most of the time, some of the time, or never.

Participants talk about community activities occurring outside of the setting.

	Percent (<i>n</i>)
All of the time	41.0% (163)
Most of the time	29.1% (116)
Some of the time	28.4% (113)
Never	1.5% (6)

Participants have the opportunity to engage in community activities while at the setting (both at the setting and in the community).

	Percent (<i>n</i>)
All of the time	35.8% (142)
Most of the time	29.0% (115)
Some of the time	32.2% (128)
Never	3.0% (12)

Participants and community members interact at the setting.

	Percent (<i>n</i>)
All of the time	25.1% (100)
Most of the time	17.1% (68)
Some of the time	52.0% (207)
Never	5.8% (23)

How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Participants do NOT know where to find information on community activities.

	Percent (<i>n</i>)
Strongly agree	3.3% (13)
Somewhat agree	9.6% (38)
Neither agree nor disagree	20.9% (83)
Somewhat disagree	26.2% (104)
Strongly disagree	40.1% (159)

There are setting rules that prohibit participants from coming and going as they please.

	Percent (<i>n</i>)
Strongly agree	25.1% (100)
Somewhat agree	31.4% (125)
Neither agree nor disagree	12.6% (50)
Somewhat disagree	11.6% (46)
Strongly disagree	19.3% (77)

Participants are given easy access to the community outside of the setting.

	Percent (<i>n</i>)
Strongly agree	32.6% (130)
Somewhat agree	34.8% (139)
Neither agree nor disagree	17.5% (70)
Somewhat disagree	10.3% (41)
Strongly disagree	4.8% (19)

Is helping participants obtain integrated employment opportunities part of your service?

	Percent (<i>n</i>)
Yes	59.9% (227)
No	40.1% (152)

Only answer these questions if you answered “yes” to the question above. If your setting does not provide employment opportunities, please continue to the next page.

Please select whether the following occur all of the time, most of the time, some of the time, or never.

Participants pursue integrated /competitive employment opportunities.

	Percent (<i>n</i>)
All of the time	22.9% (57)
Most of the time	14.9% (37)
Some of the time	56.6% (141)
Never	5.6% (14)

Participants pursue other employment opportunities (both paid and volunteer).

	Percent (<i>n</i>)
All of the time	26.5% (66)
Most of the time	20.5% (51)
Some of the time	48.2% (120)
Never	4.8% (12)

Interested participants are given the resources on how to obtain employment.

	Percent (<i>n</i>)
All of the time	66.3% (165)
Most of the time	20.1% (50)
Some of the time	10.8% (27)
Never	2.8% (7)

Personal Accommodations (Dining and Travel)

The next set of questions deal with travel accommodations provided by your non-residential setting. We are interested in the transportation opportunities and access at your setting. How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

There are NO public transportation opportunities available to participants to/from the setting.

	Percent (<i>n</i>)
Strongly agree	8.9% (36)
Somewhat agree	11.6% (47)
Neither agree nor disagree	3.5% (14)
Somewhat disagree	27.7% (112)
Strongly disagree	48.4% (196)

The setting provides transportation opportunities to participants outside of regularly schedule options.

	Percent (<i>n</i>)
Strongly agree	36.2% (146)
Somewhat agree	31.3% (126)
Neither agree nor disagree	5.2% (21)
Somewhat disagree	14.6% (59)
Strongly disagree	12.7% (51)

Are retail businesses near your setting?

	Percent (<i>n</i>)
Yes	83.2% (332)
No	16.8% (67)

Does your setting provide regularly scheduled transportation opportunities to participants? (This includes transportation to community activities, transportation to community services, transportation to/from setting).

	Percent (<i>n</i>)
Yes	90.3% (363)
No	9.7% (39)

Only answer these questions if you answered “yes” to the questions above. If your setting does not provide transportation opportunities, please continue to the next page.

Please select whether the following occur all of the time, most of the time, some of the time, or never.

Participants are informed/educated on how to use public transportation opportunities.

	Percent (<i>n</i>)
All of the time	57.9% (212)
Most of the time	21.6% (79)
Some of the time	18.0% (66)
Never	2.5% (9)

Participants use the transportation opportunities provided by the setting.

	Percent (<i>n</i>)
All of the time	65.6% (239)
Most of the time	25.2% (92)
Some of the time	9.0% (33)
Never	0.3% (1)

Participants know how to contact a staff member about transportation opportunities.

	Percent (<i>n</i>)
All of the time	64.5% (236)
Most of the time	21.9% (80)
Some of the time	12.0% (44)
Never	1.6% (6)

How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Transportation opportunities are limited for participants.

	Percent (<i>n</i>)
Strongly agree	15.9% (58)
Somewhat agree	33.2% (121)
Neither agree nor disagree	9.0% (33)
Somewhat disagree	24.4% (89)
Strongly disagree	17.5% (64)

Participants feel confident using the transportation opportunities provided by the setting.

	Percent (<i>n</i>)
Strongly agree	76.5% (280)
Somewhat agree	17.8% (65)
Neither agree nor disagree	3.8% (14)
Somewhat disagree	0.8% (3)
Strongly disagree	1.1% (4)

Does your setting provide a space for participants to have a meal at the setting?

	Percent (<i>n</i>)
Yes	95.0% (384)
No	5.0% (20)

Only answer these questions if you answered “yes” to the questions above. If your setting does not provide dining/food accommodations, please continue to the next page.

Participants are assigned seating during meal-times.

	Percent (<i>n</i>)
Strongly agree	3.4% (13)
Somewhat agree	13.6% (52)
Neither agree nor disagree	5.5% (21)
Somewhat disagree	13.8% (53)
Strongly disagree	63.7% (244)

Participants are able to set their own dining/meal-time schedule.

	Percent (<i>n</i>)
Strongly agree	9.9% (38)
Somewhat agree	15.4% (59)
Neither agree nor disagree	9.6% (37)
Somewhat disagree	32.3% (124)
Strongly disagree	32.8% (126)

Participants do NOT engage with others during meal-times.

	Percent (<i>n</i>)
Strongly agree	1.6% (6)
Somewhat agree	0.3% (1)
Neither agree nor disagree	1.3% (5)
Somewhat disagree	7.9% (30)
Strongly disagree	89.0% (339)

Does your setting provide or arrange for meals and food for participants while at the setting?

	Percent (<i>n</i>)
Yes	35.6% (143)
No	64.4% (259)

When it comes to dining/food options, would you say that a typical individual has a lot of choice, some choice, or no choice at all?

	Percent (<i>n</i>)
A lot of choice	22.4% (32)
Some choice	74.8% (107)
No choice at all	2.8% (4)

Please select whether the following occur all of the time, most of the time, some of the time, or never.

There is more than one meal option during meal-times.

	Percent (<i>n</i>)
All of the time	35.7% (51)
Most of the time	25.2% (36)
Some of the time	27.3% (39)
Never	11.9% (17)

Between designated meal-times, the setting provides other food or refreshments.

	Percent (<i>n</i>)
All of the time	60.8% (87)
Most of the time	14.0% (20)
Some of the time	18.9% (27)
Never	6.3% (9)

Personal Autonomy and Choice in Care Options

The next set of questions deals with individual choice when it comes to their care and services provided.

First, we are interested in how often participants are asked about their needs and preferences.

Thinking about the average individual at your setting, were they asked about their goals and aspirations in the past 12 months?

	Percent (<i>n</i>)
Yes	97.1% (368)
No	1.6% (6)
Don't know	1.3% (5)

How often, if at all, do participants make changes to their plan of care?

	Percent (<i>n</i>)
Never	0.6% (2)
Annually	10.0% (36)
Semi-annually	16.7% (60)
Monthly	3.1% (11)
As needed/ requested	69.7% (251)

Please select whether the following occur all of the time, most of the time, some of the time, or never.

Individual complaints are addressed in a timely manner.

	Percent (<i>n</i>)
All of the time	77.9% (299)
Most of the time	22.1% (85)
Some of the time	0% (0)
Never	0% (0)

Participants make changes to their plan of care as needed.

	Percent (<i>n</i>)
All of the time	57.8% (222)
Most of the time	24.7% (95)
Some of the time	14.8% (57)
Never	2.6% (10)

Participants with concerns, discuss the concerns with the setting staff.

	Percent (<i>n</i>)
All of the time	67.5% (258)
Most of the time	28.0% (107)
Some of the time	3.7% (14)
Never	0.8% (3)

Participants provide input into their daily schedules.

	Percent (<i>n</i>)
All of the time	45.8% (175)
Most of the time	35.9% (137)
Some of the time	17.3% (66)
Never	1.0% (4)

Staff members do NOT discuss participants with other staff members in public spaces.

	Percent (<i>n</i>)
All of the time	71.9% (274)
Most of the time	18.9% (72)
Some of the time	2.1% (8)
Never	7.1% (27)

When an individual files a complaint, it is considered confidential.

	Percent (<i>n</i>)
All of the time	92.4% (355)
Most of the time	7.0% (27)
Some of the time	0.3% (1)
Never	0.3% (1)

When needed, participants know how to request a new/additional service.

	Percent (<i>n</i>)
All of the time	39.4% (151)
Most of the time	42.8% (164)
Some of the time	16.4% (63)
Never	1.3% (5)

Participants have the opportunity to express their level of satisfaction with the services they are receiving.

	Percent (<i>n</i>)
All of the time	89.7% (341)
Most of the time	7.9% (30)
Some of the time	2.4% (9)
Never	0% (0)

How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Participants do NOT feel comfortable expressing concerns regarding their care.

	Percent (<i>n</i>)
Strongly agree	1.0% (4)
Somewhat agree	1.3% (5)
Neither agree nor disagree	3.9% (15)
Somewhat disagree	16.4% (63)
Strongly disagree	77.9% (297)

Participants do NOT know how make changes to their plans of care.

	Percent (<i>n</i>)
Strongly agree	0.8% (3)
Somewhat agree	10.8% (41)
Neither agree nor disagree	11.3% (43)
Somewhat disagree	32.5% (124)
Strongly disagree	44.6% (170)

Information on how to file a complaint is easily accessible to participants.

	Percent (<i>n</i>)
Strongly agree	68.7% (263)
Somewhat agree	18.3% (70)
Neither agree nor disagree	5.5% (21)
Somewhat disagree	2.1% (8)
Strongly disagree	5.5% (21)

Participants do NOT have a choice of which provider staff delivers care/support.

	Percent (<i>n</i>)
Strongly agree	4.5% (17)
Somewhat agree	22.0% (84)
Neither agree nor disagree	13.6% (52)
Somewhat disagree	25.9% (99)
Strongly disagree	34.0% (130)

Individual requests regarding their care are forwarded to independent/non-setting based case manager.

	Percent (<i>n</i>)
Strongly agree	40.6% (155)
Somewhat agree	24.3% (93)
Neither agree nor disagree	12.8% (49)
Somewhat disagree	8.4% (32)
Strongly disagree	13.9% (53)

Schedules for PT, OT, medication, diet, or other care options are posted in common areas (i.e., hallways).

	Percent (<i>n</i>)
Strongly agree	7.3% (28)
Somewhat agree	6.8% (26)
Neither agree nor disagree	14.4% (55)
Somewhat disagree	8.1% (31)
Strongly disagree	63.3% (241)

Appendix D**PUBLIC NOTICE**

Statute requiring agency to publish information concerning proposed changes in methods and standards for establishing medical assistance payment rates for medical services in the Illinois Register: 5 ILCS 100/5-70(c)

Summary of information: Home and Community-Based Services (HCBS) Settings Draft Transition Plan Illinois Department of Healthcare and Family Service:

The Illinois Department of Healthcare and Family Services (HFS) gives notice that the DRAFT Statewide Transition Plan, required by the Centers for Medicaid and Medicare Services (CMS) Home and Community-Based Services (HCBS) Rule 42 CFR 441.301(c)(iii), will be available for public review and comment for a period of 30 days beginning on 01/15/2015 and ending on 02/15/2015. HFS is required to submit the final Statewide Transition Plan to CMS no later than 03/17/2015. The Department of Health and Human Services' Centers for Medicare and Medicaid Services (CMS) published regulations in the Federal Register (42 CFR 441.301(c) (4)-(5)) on January 16, 2014, effective March 17, 2014, which further clarifies the definition of home and community-based services (HCBS) residential and non-residential settings for section 1915(c) Medicaid Waivers and approved state plans providing HCBS under section 1915(i). The new rules require states to develop a Statewide Transition Plan identifying the strategies for compliance with the new regulations and allowing up to five years for full compliance.

The DRAFT Statewide Transition Plan covers all nine HCBS waivers and is expected to detail the level of current compliance and the actions the state will take to achieve compliance with the HCBS Setting requirements. Once posted, the DRAFT Statewide Transition Plan can be viewed at the website of the Illinois Department of Healthcare and Family Services (HFS), Medical Programs, Home and Community Based Waiver Programs; <http://www2.illinois.gov/hfs/MedicalPrograms/HCBS/Pages/default.aspx>. Comments may be submitted on this site. Persons who are unable to access the Internet may request a hard copy of the DRAFT Plan by calling HFS at (217) 557-1868.

Name and address of person to contact concerning this information:

The Illinois Department of Healthcare and Family Services
Attn: Waiver Management
201 South Grand Ave East, 2nd FL
Springfield, IL 62763

Public Forums have been scheduled across the state. At these forums, the public will have the opportunity to provide verbal and written comment. A request is made that comments be submitted in written form, as well as voiced, in order to guarantee that they are recorded correctly. Persons who are unable to attend a Public Forum or submit comments using the Internet, may phone in their comments by calling HFS at (217) 557-1868 or mail written feedback to the address listed above.

Public comments are requested from 01/15/2015 through 02/15/2015. Public comments will be summarized and included in the revised Statewide Transition Plan. The public is encouraged to attend one of the forums listed below.

PUBLIC FORUM SCHEDULE		
Thursday January 29, 2015	Parkland College RoomW-115 2400 West Bradley Ave Champaign, IL 61821	10:30am – Noon
Thursday January 29, 2015	EP!C 1913 West Townline Rd Peoria, IL 61612	3:00pm – 4:30pm
Tuesday February 3, 2015	Spring Ridge Senior Housing Community Room 6645 Fincham Dr Rockford, IL 61108	1:30pm – 3:00pm
Wednesday February 4, 2015	University of Illinois-Chicago Disability, Health & Social Policy Building Auditorium, Room 166 1640 West Roosevelt Rd Chicago, IL 60608	10:30am – Noon
Wednesday February 4, 2015	The ARC 20901 LaGrange Rd, Suite 209 Frankfort, IL 60423	2:00pm – 3:30pm
Tuesday February 10, 2015	Rend Lake College Student Center – Private Dining Area 468 North Ken Gray Parkway Ina, IL 62846	1:00pm – 2:30pm

Appendix E**SECOND PUBLIC NOTICE**

TO BE INSERTED

(Only anticipated change will be to extend the public comment period through February 24, 2015)

Appendix F

FLYER

New Medicaid Rules Apply to Home & Community Based Waiver Settings

The State of Illinois operates nine HCBS waivers.

- Adults with Developmental Disabilities Waiver
- Children and Young Adults with Developmental Disabilities Residential Waiver
- Children and Young Adults with Developmental Disabilities Support Waiver
- Children that are Technology Dependent/Medically Fragile Waiver
- Persons with Disabilities Waiver
- Persons with Brain Injury Waiver
- Persons who are Elderly
- Persons with HIV or AIDS
- Supportive Living Facilities

Illinois is required by the federal Centers for Medicaid & Medicare Services (CMS) to submit a Statewide Transition Plan indicating how we will comply with the new rules. A major component of the Statewide Plan is obtaining feedback from stakeholders. Public comments are requested for 30 days upon release of the Draft Statewide Transition Plan. Once posted, you can view Illinois' DRAFT Transition Plan as well as links to the new CMS rules and additional CMS guidance at:

<http://www2.illinois.gov/hfs/MedicalPrograms/HCBS/Transition/Pages/default.aspx>. Comments can be submitted directly through the website. Persons without Internet access can call HFS at (217) 557-1868 to request a hardcopy.

The State of Illinois requests your input on the DRAFT Statewide Transition Plan**Regional Public Listening Forums:**

The State has scheduled Regional Public Listening Forums across the state where the public will have the opportunity to provide verbal and written comment. Comments should be submitted in written form, as well as voiced, in order to guarantee that they are recorded correctly. Persons who are unable to attend a Public Listening Forum or submit comments using the Internet, may phone in their comments by calling HFS at (217) 557-1868 or mail written feedback to: Illinois Department of Healthcare and Family Services, Attn: Waiver Management, 201 South Grand Ave East, 2nd FL, Springfield, IL 62763

The public is encouraged to attend one of the Public Listening Forums listed below.

Thursday, January 29, 2015 10:30am – Noon	Parkland College	Room W-115, 2400 West Bradley Ave Champaign, IL 61821
Thursday, January 29, 2015 3:00pm – 4:30pm	EPIC	1913 West Townline Rd Peoria, IL 61612
Tuesday, February 03, 2015 1:30pm – 3:00pm	Spring Ridge Senior Housing	Community Room, 6645 Fincham Dr Rockford, IL 61108
Wednesday, February 04, 2015 10:30am – Noon	University of Illinois - Chicago	Disability, Health & Social Policy Building Auditorium, Room 166, 1640 West Roosevelt Rd Chicago, IL 60608
Wednesday, February 04, 2015 2:00pm – 3:30pm	The ARC	20901 LaGrange Rd, Suite 209 Frankfort, IL 60423
Tuesday, February 10, 2015 1:00pm – 2:30pm	Rend Lake College	Student Center – Private Dining Area 468 North Ken Gray Parkway Ina, IL 62846

Webinar: New Medicaid Waiver Rules Draft Statewide Transition Plan Listening Webinar

Wednesday, February 11, 2015

9:00 am to 10:00 am

Register at:

<https://attendee.gotowebinar.com/register/6935166657459007233>

Appendix G

Action Steps and Timeline to Bring Illinois into Compliance

Chart of Action Steps and Timetable to Bring Illinois into Compliance				
	Action Item	Strategy	Initial Start Date	Projected End Date
1	Initial Transition Plan Development	The State holds a series of meetings with internal stakeholders to present new federal Medicaid regulations which apply to all HCBS programs, including all 1915 c waivers, and to solicit input on the development of the Statewide Transition Plan.	4/1/2014	3/16/2015
2	Assessment of Settings	State engages University of Illinois at Springfield (UIS) to assist with the development of two surveys -- Residential and Non-Residential Settings -- and to develop an implementation plan that includes the methodology for surveying all HCBS settings in order to gather basis information which will be used to inform the compliance status with the new requirements.	8/1/2014	1/15/2015
	Survey of HCBS Residential Settings	The Residential Survey consists of two surveys: one which is agency-specific and another which is setting-specific. Surveys are mailed, completed, submitted to UIS.	10/5/2014	12/15/14
	Survey of HCBS Non-Residential Settings	The Non-Residential Survey consists of two surveys: one which is agency-specific and another which is setting-specific. Surveys are mailed, completed, submitted to UIS.	11/1/2014	1/15/2015
	Individual site reviews to validate survey results	UIS will assist the State in stratifying the survey results into categories reflecting likely compliance status.. The State will validate the survey results via on-site visits to a sampling of sites in each of the categories.	3/17/2015	9/15/2016
	Individual consumer interviews at sites	Where possible, small on-site focus groups will be held to complete structured conversations re: choice, community integration, impact of new rule on participant lives; also, individual interviews with participants on-site will take place.	3/17/2015	9/15/2016
	Settings Analysis	Analysis of survey results; areas needing to be addressed in order to comply with new rule will be identified; UIS is to provide Executive Summary as well as full detailed report.	11/1/2014	2/15/2015

	Analysis by type of service and location after completion of site visits	<p>Review of supporting documents provided by the providers; classification of settings into:</p> <ul style="list-style-type: none"> • those which appear to be fully compliant; • those needing to make changes in order to comply; • those who are presumed to be non-compliant, but may present countering evidence under the heightened scrutiny review; and • those who do not comply. 	3/17/2015	12/31/2016
3	Assessment of Infrastructure			
	Legal and program staff review of current administrative rules/statutes/waiver definitions	Review of current residential agreements, including State, provider and specific site policies, rules and procedures relating to employment and day services for non-residential settings.	6/1/2014	12/31/2016
	Review of current State and setting forms, program policies and procedures	Review language used; evidence of choice; service options; employment preparation/assistance; identify materials needing remediation.	3/17/2015	9/15/2016

4	Communication/Public Input			
	Public notices informing participants of rule, website, welcoming input, providing schedule of upcoming public events, Phone/USPS Mail	Notices are to be distributed through email to providers and advocacy groups who will be asked to further distribute this information to their participants/members; Notices will also be published on the HFS website as well as the Illinois Register, if applicable; Phone number and USPS mailing address will be provided to receive requests for hard copies of the Transition Plan as well as to receive comments.	1/15/2015	Ongoing
	Website	Transition Plan DRAFT will be posted on the state's HFS website; comment box is provided on website for comments and questions; dates and locations of public forums will be listed on website; public comments will be posted to the website; the website will also list general guidance to be offered to providers re: compliance.	1/15/2015	Ongoing
	Public and Stakeholder Educational Forums/Listening and Feedback Sessions	Six public forums are to be held at geographically diverse, accessible locations across the state.	1/15/2014	2/15/2015
	Webinars	Two webinars will be held: one primarily for providers/provider organizations and one primarily for participants and their families/guardians/representatives.	1/15/2015	2/15/2015
	Written materials: DRAFT Transition Plan and Survey summaries	Copies will be provided to regional CMS Project Officer.	1/16/2015	1/16/2015
	Revisions to the Transition Plan	Based on public comment via the website, forums, and mailed responses, as appropriate, the Transition Plan will be revised; a summary document of all public submitted comments will be attached to the Plan submitted to CMS.	1/15/2015	3/16/2015

5	Remediation Strategies			
	Required modifications to existing administrative rules/statutes/waiver definitions (<i>Specific Rule/Statutes may be found in Appendix A</i>)	Identify required modifications to each administrative rule, statute and waiver definition; Review and develop recommendations for language changes and drafts of new forms and agreements; Obtain legal approval; Implement modification. Some of these changes may require legislative action and/or waiver amendment.	1/1/2016	1/1/2019
	Required modifications and/or creation of new forms/agreements	Development and implementation of new resident agreements, where needed, to comport with residential settings rules. This also includes the development and implementation of State and site policies and procedures relating to employment and day services in non-residential settings.	1/1/2016	1/1/2019
	Training	Training will be provided to care coordinators, service coordinators, residential staff, and credentialing and protective service staff on changes to policies and procedures due to the HCBS rules. Among the topics to be covered are: individual rights, informed choices, person-centered planning, protections, community inclusion, and working with high-risk individuals.	1/15/2015	On-going
		Training/education will also be provided for participants and families regarding compliance with the new rule and changes that may be made to their HCBS settings.		

	Individual provider assessment findings	Notices are to be sent to providers who are not in compliance or presumed not to be in compliance. Explanation is to be provided as to why their settings do not meet the criteria outlined in the new rule, the actions needed and the timeframes for the settings to become compliant.	9/16/2016	3/1/2017
	Process to be used with settings under Heightened Scrutiny	<p>Sites which appear to be out of compliance with the requirements of the regulation:</p> <ul style="list-style-type: none"> • those adjacent to, or on the grounds of, public institutions; • those located in a facility which provides inpatient treatment; and • those which seem not to provide the opportunity for participants to receive services in the most integrated community settings <p>Determinations will be made on a case-by-case basis. Additional information may be provided by the site and a site visit will take place. Materials will be presented to CMS.</p>	3/16/2016	12/31/2016
	Provider sanctions and disenrollment	State will de-certify and/or sanction providers who have failed to complete their remediation plans or have failed to be cooperative with the transition of the HCBS settings.	1/1/2018	On-going

	Individual participant transitions	If necessary, the State will work with individual providers to develop transition plans for participants residing or participating in non-compliant settings. Transitions will occur only after all options have been exhausted. Care coordinators, program staff and other individuals involved in the participants' care will join in the decision-making regarding an alternative residence or service location. State will ensure that all participants have a safe transition plan before any relocation or transition occurs.	1/1/2018	On-going
6	Ongoing Compliance			
		Activities which may be components of maintaining ongoing compliance with the new rule will include:		
		<ul style="list-style-type: none"> an annual review of the participant's person-centered plan, during which feedback will be sought from the participant and the participant's family or guardian regarding the access to community activities, choice of accommodations, roommates, and services. In addition, the annual review should validate the inclusion of participant goals and satisfaction with services. 	1/1/2018	On-going
		<ul style="list-style-type: none"> onsite inspections/audits which include collection of data re: factors described in the new rule (choice, options, community integration); 	1/1/2018	On-going
		<ul style="list-style-type: none"> implementation of the Quality Assurance Plan for each waiver, described in Appendix H of each waiver and modified as necessary to incorporate rules 	1/1/2018	On-going
		<ul style="list-style-type: none"> QA monitoring of Assurances and Performance Measures; 	1/1/2018	On-going
		<ul style="list-style-type: none"> The HFS website will remain active and its comment box will remain available to those in the community who would like to file complaints or make comments about the policies and procedures at particular settings that appear non-compliant with rule requirements. 	1/15/2015	On-going

		<ul style="list-style-type: none">• Sites found to be out of compliance during any routine assessments will be required to complete a corrective action plan.	1/1/2017	On-going
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